

DOCTORAL THESIS

Living with Parkinsonism

Does dance help improve the quality of movement, functions and everyday activities?

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**Living with Parkinsonism: Does dance help improve the quality
of movement, functions and everyday activities?**

by

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**A thesis submitted in partial fulfilment of the requirements for
the degree of PhD**

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Abstract

The following thesis aims to understand the physical, mental, emotional, and social benefits of a weekly ballet class for people living with Parkinson's. Although dance has shown to be a beneficial activity for this group of people, recent research has placed a strong emphasis on the physical benefits. There is a lack of research looking at how participation in dance may also impact upon activities of daily living and level of participation in society. The present thesis proposes a new framework for dance for Parkinson's research that places equal emphasis on these factors while also recognising how personal and environmental contextual factors may play a role in how the dance classes are experienced. To assess changes across a two-year time period the study used a mixed methods approach and used a control group of people with Parkinson's who did not take part in dance. Quantitative assessments included biomechanical measures of gait (step and stride variability, trunk coordination, and trunk range of motion), the Unified Parkinson's Disease Rating Scale (UPDRS), the Activities-Specific Balance Confidence (ABC) scale, and the Dance for Parkinson's Questionnaire (DPQ). Qualitative assessments included one-to-one semi-structured interviews, focus group discussions, informal conversations with participants, and observation of the ballet classes. Quantitative results demonstrated a lack of significant physiological change when assessing the group as a whole. However, individual case studies revealed that some dancing participants saw clinically meaningful change across time with respect to variables assessing physical functioning. Qualitative data demonstrated that participants valued the ballet classes for a variety of reasons. Comments from

interviews and group discussions showed that the social inclusion, the level of enjoyment gained from moving to music, the cultural and educational experiences were all reasons why participants continued to attend the classes and gain benefit from them. Although the present thesis did not demonstrate significant physical benefit from the weekly ballet classes, qualitative data suggests that participants gained important psychological, social, and emotional benefit as a result of participating in this programme.

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List of Abbreviations

6MWT – 6-minute Walk Test
ABC Scale – Activities-Specific Balance Confidence Scale
ACSM – American College of Sports Medicine
ADL – Activities of Daily Living
ADTA – American Dance Therapy Association
APPDE - Association of Physiotherapists in Parkinson’s Disease Europe
ASC – Activity Sort Card
BA – Bachelor of Arts
BBS – Berg Balance Scale
CDC - Centre for Disease Control and Prevention
CES-D - Centre for Epidemiologic Studies Depression Scale
COM – Centre of Mass
DA – Dopamine Agonist
DBS – Deep Brain Stimulation
DPQ – Dance for Parkinson’s Questionnaire
ENB – English National Ballet
EPDA – European Parkinson’s Disease Association
FAB Scale – Fullerton Advanced Balance Scale
FITT – Frequency, Intensity, Timing, Type
fMRI - Functional Magnetic Resonance Imaging
H&Y – Hoehn and Yahr
ICF – International Classification of Functioning, Disability, and Health
ICIDH - International Classification of Impairment, Disability, and Handicap
MbM Therapy – Music-based Movement Therapy
MCIC – Minimal Clinically Important Change
MDS – Movement Disorder Society
MMSE – Mini-Mental State Examination
NICE – National Institute for Health and Care Excellence
PD – Parkinson’s Disease
PDQ-39 – 39-item Parkinson’s Disease Questionnaire
PDS – Parkinson’s Disease Society
PET - Positron Emission Tomography

QOLS – Quality of Life Scale

ROM – Range of Motion

SD – Standard Deviation

SF-36 – 36-item Short Form Health Survey

TUG – Timed Up and Go

UPDRS – Unified Parkinson’s Disease Rating Scale

WHO – World Health Organisation

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Ethical Approval Statement

The research for this project was submitted for ethics consideration under the reference 12/ 006 in the Department of Dance and was approved under the procedures of the University of Roehampton's Ethics Committee on the 4th of September, 2012.

Chapter One

Introduction

1.1 Overview and Rationale for Study

Over one million people are currently living with Parkinson's across Europe, with approximately 127,000 people living with the condition in the United Kingdom alone (EPDA, 2012). The economic impact of Parkinson's is large with an estimated annual European cost in 2011 of 13.9 billion euros (Gustavsson et al. 2011; EPDA, 2012), a cost that is predicted to substantially increase as the number of people with Parkinson's grows within the ageing population.

Although there are a variety of medications available to help people cope better with their symptoms, there are numerous limitations to these medicines including decreased efficacy over time and a range of complications or side effects. Furthermore, it appears that these medicines do not necessarily address all symptoms and thus people may still find themselves socially isolated and avoiding participation in society (Brooks, 2008; Cummings, 1992).

There has been a recent move in treatment for people with Parkinson's to include the use of alternative therapies and exercise alongside drug therapy with the aim of helping to manage some of the limitations and concerns addressed above. It has been noted in recent research that the inclusion of non-pharmacological treatment options may help to address some of the symptoms not affected by drug therapy. In turn this may help to decrease the total economic impact including costs of Parkinson's worldwide and expenditures for people with Parkinson's (EPDA, 2012; Olanow et al., 2009).

Recent research has noted dance as a beneficial alternative therapy for people with Parkinson's (Hackney et al., 2007; Hackney and Earhart, 2009a; 2009b; Houston and McGill, 2013). Physically, dance may help to provide movement exercises that focus on flexibility, muscular strength and endurance, coordination patterns, posture, balance, and agility. By way of taking part in this kind of activity, symptoms including rigidity, lack of coordination, loss of balance and stability, increased fall risk, and a stooped posture may be alleviated or improved (Shanahan et al., 2015; Earhart, 2009; Houston and McGill, 2013). Dance has also been recognized as an enjoyable activity for many participants leading to an increase in motivation to be physically active and furthermore an improved sense of confidence and self-esteem (Heiberger et al, 2011; Houston and McGill 2013). It is a form of exercise that allows for positive social interaction with others who are dealing with the condition and thus may help participants to cope with feelings of depression, social isolation, and loneliness (Hackney and Earhart, 2009b; Heiberger et al., 2011; Westheimer, 2008). As a result of these physical, psychological, social, and emotional benefits, participation in dance may lead to an improved sense of wellbeing and enhanced quality of life for people with Parkinson's.

While recent research has demonstrated a number of positive benefits from participation in dance, there appears to be a strong emphasis placed on how dance can improve physical symptoms with a lack of understanding of how physical, psychological, social and emotional benefits interrelate with one another to lead to an improved quality of life for the individual. As of yet research has not fully demonstrated how changes to functional mobility, balance,

and gait connect to and correlate with feelings of an improved sense of wellbeing and other quality of life factors. Through having an understanding of these connections and relationships this thesis can further discuss how meaningful any physical changes are to the individuals partaking in dance, thus gaining more insight into the impact dance is having on this population.

1.2 Overview of Thesis Chapters

1.2.1 Chapter Two

The literature review will provide insight into current research in the dance for Parkinson's field and further rationalize the need for the inclusion of dance as an alternative therapy for people living with Parkinson's. In order to argue for this more holistic approach to treatment, there is a need to understand and briefly describe the nature of the condition, the advantages and disadvantages of current treatment options, and the full economic costs of treatment and care. The argument for the inclusion of alternative therapies and physical activity alongside drug therapy will be made with a review of current research outlining the potential benefits of physiotherapy and exercise for people living with Parkinson's.

This chapter will outline my stance on current research in the dance for Parkinson's field and will discuss the apparent lack of study on how dance can affect individuals with Parkinson's physically, mentally, emotionally, and socially. The chapter will then conclude with a recommendation for future

research in the field that encourages the use of an internationally recognized framework to help address some of the concerns that have been found through an in-depth literature review.

1.2.2 Chapter Three

Chapter Three will begin with a discussion of the ontological and epistemological approaches used for the present thesis and will argue for the use of a mixed methods approach. The research aims and questions will be outlined for the reader with a clear statement addressing the hypotheses for the study. After these initial subsections the context of the study in relation to the wider project between University of Roehampton and English National Ballet (ENB) will be described and the specific aims of the present thesis will be outlined. Participant recruitment methods will be discussed in relation to the design of the project. The basic structure and ethos of the ballet classes at ENB will be fully described with an emphasis on how the classes focused on the learning of ballet as an art form rather than treating it as a therapy. The primary structure and types of exercises involved in the weekly ballet classes will be discussed and the process by which these exercises were choreographed briefly explained.

Overall participant characteristics will be outlined. Although participant characteristics will also be brought forward in later chapters within the thesis, it is important to note that each measurement will have a different sample size as a result of some participants not taking part in all assessments. As such, some chapters may focus on a smaller number of participants depending on the

variables to be discussed. It is therefore necessary to first look at participants in relation to the whole project before narrowing in on specific measures.

The data collection process will be explained with a brief description of the main measurements. In relation to the variables for assessment, detailed descriptions of their connection to the underlying theoretical framework and the assessment methods used will be explained in later chapters outlining the results. Ethical considerations will be fully described in this chapter with reference to specific measurements and actions taken to reduce potential problems or hazards.

An overview of the analysis will outline how and why data gathered across a two-year time period was narrowed down to a single short-term and long-term analysis for the present study. The final section of this chapter will outline how the results will be discussed and displayed as four separate chapters and a final chapter (Chapter Eight) that looks more closely at five individual case studies.

1.2.3 Chapter Four

This chapter will focus on changes to dynamic stability as assessed via biomechanical measures of gait variability. Furthermore, gait variability results will be correlated with measures of balance confidence. The chapter will begin with a critical review of studies in the field that have aimed to assess changes to balance after a dance intervention. Arguments will be made for the need to understand how ballet specifically might impact upon dynamic stability for people with Parkinson's. Furthermore, suggestions will be made about varying

the methods used to assess this variable in dance for Parkinson's research. The results will be discussed and explained with reference to previous research in the field that has shown dance-related activity can improve balance for this group of people. Recommendations for research will be made with an emphasis on distinguishing between static and dynamic stability in future work.

1.2.4 Chapter Five

Chapter Five will look at changes in coordination and range of motion of the trunk during normal walking as assessed through the use of inertial sensors. The chapter will begin by outlining the characteristic features of Parkinsonian gait and how these factors lead to an increased fall risk for this population. Arguments will demonstrate how recent studies tend to focus heavily on changes in gait speed, however there is a general lack of research looking at other gait variables in the dance for Parkinson's field. The results will be explained with reference to recent research evidencing that people with Parkinson's tend to coordinate the trunk in a more in-phase pattern. Suggestions for future research will be made based on the resulting data.

1.2.5 Chapter Six

This chapter will look at changes to non-motor and motor impairments in relation to activities of daily living using the Unified Parkinson's Disease Rating Scale (UPDRS). The chapter will begin with a critical review of recent research in the field outlining the strong emphasis placed on how participation in dance

can help improve motor impairments. However, arguments will be made that there is a lack of research looking at how these physical changes impact upon activities of daily living for this group of people. Results will discuss any changes across time, differences between dancing and control groups, and also the relationships between the various UPDRS subscales. The chapter will refer to the World Health Organisation's International Classification of Functioning Disability and Health (ICF). A discussion will help to explain the results and will also address some concerns when applying the ICF framework to existing rating scales. Recommendations will be made for the continued study of how dance might impact upon activities of daily living.

1.2.6 Chapter Seven

Chapter Seven will look at changes to various aspects of quality life across the duration of the study. The Dance for Parkinson's questionnaire will be utilized to understand changes in perceived severity of symptoms, perceived difficulties with everyday tasks, perceived interference of illness and certainty about maintaining a positive future life. Reference will be made to the ICF and the lack of research focusing on how changes in physical impairment might impact upon activities of daily living and participation in society for this group of people. Connections will be drawn between quality of life and activity participation with recent research indicating a positive correlation between the two. Results will discuss each subscale of the questionnaire separately and will look at changes across time and differences between groups. All subscales will then be correlated to look at the relationships between these aspects of quality of life. The

quantitative results will be discussed in relation to qualitative data from interviews, focus group discussions, and informal conversations with the dancing participants. Conclusions will be drawn about what aspects of the ballet classes were valued by the participants and recommendations for future research will encourage the continued study of participation and quality of life within the field.

1.2.7 Chapter Eight

This chapter will begin with an overview of Chapters Four through to Seven and will discuss how these chapters aim to address the main domains of the ICF framework. However, arguments will be made about the lack of ability to consider personal and environmental contextual factors when analysing changes to the groups as a whole. The present thesis, in accordance with the ICF, suggests that personal and environmental contextual factors should be considered when looking at changes in impairments, activities of daily living, and participation in society. This chapter will argue that the only way to appropriately consider these factors is to look at the results on a case-by-case basis. Only then will researchers be able to discuss how experiences outside of the dance studio may have been affecting how participants engaged with the ballet classes and how they performed within the testing sessions. Five case studies will be presented to evidence how personal contextual factors may have influenced participant results.

1.2.8 Chapter Nine

Chapter Nine will begin by outlining some of the key findings discussed in Chapters Four through to Eight and references will be made to later sections in the chapter that will go into further detail with specific findings. First, ideas about varying methods of balance assessment will be discussed with reference to arguments made in Chapter Four. Multiple chapters throughout the thesis suggested the need for a better understanding of the mechanisms of change and optimal guidelines for the frequency, intensity, duration, and type of dance-based activity. These ideas will be discussed further in this chapter, as will the relationships between participants' perception of change and the measured change seen across the study. Interviews, focus group discussions, and informal conversations evidence that participants valued the social interaction, the musical accompaniment, and the cultural and educational nature of the ballet classes. Further discussion about these elements will provide explanations suggesting how and why participants found these elements of the class useful.

Across the course of study, researchers were presented with some limitations. These will be outlined along with a summary of suggestions for future research in the field.

1.2.9 Chapter Ten

The concluding chapter will look to address the initial research aims and questions brought forward in Chapter Three. Each question will be looked at

separately and findings from the present thesis will be discussed in relation to these questions. The initial hypothesis will also be addressed with the aim of explaining how the results demonstrate if the proposed hypothesis was realised. The chapter aims to summarise the results and present an overview of how the ballet classes impacted upon this group of people with Parkinson's physically, mentally, emotionally, and socially.

Chapter Two

Literature Review

2.1 Parkinson's: Epidemiology and Pathology

Parkinson's is the result of the breakdown or loss of nerve cells in the substantia nigra of the brain that are responsible for producing the chemical dopamine (McAuley, 2003). The condition is characterized by a number of underlying features or traits including bradykinesia (a slowing of movement), tremor, rigidity, and loss of postural control often resulting in a stooped posture (McAuley 2003; Adams and Victor, 1993). Further physical symptoms may include loss of facial expression, decreased dynamic stability resulting in increased fall rates, difficulties with speech and expression, and loss of coordination (Kim et al., 2009). Although Parkinson's is often viewed as a condition that affects motor skills, progression of the disease can also lead to cognitive and behavioural deficits.

Non-motor symptoms can result from reduced activity in the dopamine-secreting regions of the brain. However recent research has also suggested that problems in other non-dopaminergic regions may cause some non-motor features of the condition (Chaudhuri et al., 2006; Lees et al., 2009). Common non-motor symptoms include executive dysfunction leading to problems with decision-making, initiating appropriate actions, abstract thinking, and cognitive flexibility (McAuley, 2003). Other complications may involve large fluctuations in mood, depression, anxiety, difficulties sleeping, and sensory disruption (feeling pain more severely or loss of taste and/or smell) (Jankovic, 2008). Furthermore, as a result of the myriad of physical and psychological problems, people with Parkinson's may feel isolated and alone. Individuals may lack in confidence and

find it difficult to maintain a sense of dignity in society when they cannot fully control their actions (Cummings, 1992). All of these issues combined may lead to a loss of independence and participation in the wider community and in society.

Literature suggests several possible mechanisms by which the breakdown and loss of nerve cells may occur, however many of these explanations are still not fully understood (Hirsch and Hunot, 2009). While some suggest that Lewy Body inclusions (abnormal accumulations of proteins inside nerve cells) are causing the cells to die (Obeso et al., 2010), others suggest that these cells remain intact and that protein aggregates at the pre-synapse are the main reason for degeneration (Nikolaus et al., 2009; Linazasoro, 2007; Shulz-Schaeffer, 2010). In any case, there is no cure for Parkinson's at the present time but there is a range of medications available to help people cope better with their symptoms.

2.2 Review of medical and surgical treatment options

Treatment has traditionally centred on drug therapy with levodopa being the gold standard (Tomlinson et al., 2012). Levodopa is currently one of the most common medications prescribed to people with Parkinson's and has been found to be extremely effective in symptomatic relief for the first few years. Levodopa in pill form is absorbed into the blood and carried to the brain where it is converted into dopamine. It is then stored in neurons for the body to use later in the production of movement (National Parkinson Foundation, 2015). Although Levodopa remains to be the most effective treatment for Parkinson's, it becomes

less effective across time and eventually symptoms of Parkinson's re-emerge between doses (Brooks, 2008). This is often referred to as "wearing-off" and can cause quite distinct "on" and "off" periods. In the "on" state the individual will experience the medication working properly and the symptoms will dissipate for a period of time. The "off" state is then characterized by the medication not working effectively with Parkinson's symptoms coming across clearly, thus signifying to the individual that they need to take another dosage.

Additional side effects of the medication commonly noted by people with Parkinson's include dyskinesia (involuntary movements), confusion, hallucinations or delusions, sleepiness, psychological changes, and feelings of dizziness or nausea (Brooks, 2008). Gage and Storey (2004) suggest that while anti-Parkinson medications may help to treat common symptoms such as tremor and bradykinesia, they do not sufficiently treat mobility impairments such as decreased stability, poor posture, or gait abnormalities.

Dopamine Agonists (DAs) are a group of pharmaceuticals working to activate the dopaminergic receptors that would normally be stimulated by dopamine. The DA is not changed or converted into dopamine upon entering the body, as seen with Levodopa. However, it does behave like dopamine helping to reduce symptoms caused by the loss of this neurotransmitter (Brooks, 2000). Though not as effective, this particular medication may delay the need for Levodopa, thus delaying the motor complications that come along with longer-term usage of Levodopa therapy.

Along with the two aforementioned treatment options, there are a variety of other possible medications that can be used to help reduce symptoms. Many of these medications act to improve the “plasmatic levels of levodopa and/or dopamine” (Pedrosa and Timmerman, 2013:323). More recently we have seen the inclusion of deep brain stimulation (DBS) as an efficacious therapy for different neurological symptoms, using current pulses in target areas of the brain. Pedrosa and Timmerman (2013) suggest four potential mechanisms of action at play here including a depolarizing blockade, synaptic inhibition, synaptic depression, and simulation-induced disruption of pathological network activity. Although proven effective multiple times, this form of treatment does come with medical concerns and patients being exposed to the risks of surgery. As such, it is recommended that a wide range of professionals who have an understanding of the patient and their medical history be involved in the decision or recommendation for DBS (Pedrosa and Timmerman, 2013; Jankovic and Aguilar, 2008).

2.3 Economic Impact of Parkinson’s on Society

Research suggests that Parkinson’s is the second most common neurodegenerative disease (after Alzheimer’s) affecting one percent of the total population over the age of 50 (Adams and Victor, 1993; Dorsey et al., 2007). The European Parkinson’s Disease Association (EPDA) state that more than one million people are living with the condition in Europe, a number that is predicted to double by 2030 due to the ageing population. An estimated 127,000 people are currently living with Parkinson’s in the United Kingdom alone (Andlin-Sobocki et al., 2005; Dorsey et al., 2007; EPDA, 2012).

As mentioned in the introductory paragraphs, the economic impact of Parkinson's is large with an estimated annual European cost in 2011 of 13.9 billion euros (Gustavsson et al., 2011; EPDA, 2012). Findley (2007) suggests that the total cost of Parkinson's in the United Kingdom has been estimated to be between 449 million pounds and 3.3 billion pounds annually depending on the cost model and prevalence model used. With large predicted increases in the Parkinson's population over the next 15 to 16 years, the annual cost will also increase substantially.

Chen (2008) states that it costs approximately 8,300 euros more annually in healthcare bills for each person with Parkinson's compared to someone who does not suffer from the condition. This increased cost can be attributed to longer hospital stays, more days in long-term care such as nursing homes, and increased number of prescriptions. The national economic burden of Parkinson's in the United States per year is estimated to be in excess of \$14.4 billion dollars. Furthermore the Parkinson's population in the United States "incurred medical expenses of approximately 14 billion in 2010, \$8.1 billion higher (\$12,800 per capita) than expected for a similar population without Parkinson's," (Kowal et al., 2013:311).

Multiple studies have revealed significant increases in the annual cost of a person with Parkinson's as the disease becomes more severe (Winter et al., 2010; Findley et al., 2011). Moreover, recent studies have also shown significant increases in expenditure for a person with Parkinson's as the disease progresses

(Hagell et al., 2002; Dodel et al., 2008; Findley, 2007), with non-motor symptoms being a major reason for hospitalization.

In their 2012 report the EPDA bring forth a comment by Olanow et al. (2009) stating that many recent studies have shown early drug treatment combined with therapeutic interventions can reduce the economic impact of Parkinson's. Furthermore, the combination of therapeutic and drug treatment may help to slow the progression of certain symptoms thereby maintaining quality of life for the individual in the longer term (EPDA, 2012). Those who take an active approach to dealing with the condition and choose to help themselves in gaining back a certain amount of bodily control can participate more fully in society and have a better opportunity to maintain or improve quality of life (WHO, 2003). In recent years there has been a push towards including alternative therapies into individual treatment programmes. A survey carried out by Parkinson's UK in 2008 suggests that 54% of the 13,000 members had been seen by a physiotherapist, an increase from 27% in 1998 (Parkinson's Disease Society, 2008b; Yarrow, 1999). This finding demonstrates that physical therapy is becoming far more integrated into suggested treatment regimes.

2.4 The Need for Non-Pharmacological Treatment Options for people living with Parkinson's

The argument for including non-pharmacological therapies in the treatment for people with Parkinson's is growing stronger. It is now understood that these therapies not only have the potential to improve quality of life whilst decreasing

economic impact/cost, but also may help to address symptoms that are not affected by drug therapy (Bloem et al, 2001; Poewe & Mahlknecht, 2009; Šumec et al., 2015). In a recent review study, Allen et al. (2013) concluded that 60.5% (range of 35 to 90%) of participants reported falling at least once with 39% (range of 18 to 65%) reporting recurrent falls. In their findings they came across numerous studies suggesting factors associated with recurrent falls and these factors include things like disease severity, impaired mobility, impaired balance, and freezing of gait. However, it appears that increased levodopa dosage and treatment with dopamine agonists are also associated with recurrent falls (Allcock et al., 2009; Matinolli et al, 2011). These findings suggest that prescribed medications are not helping to improve functional mobility or balance to effectively decrease fall risk. Gage and Storey (2004) concluded that non-pharmacological interventions might help to improve variables not addressed by the medications, such as balance and functional mobility, and thus help to improve important aspects of an individual's wellbeing.

As medications can cause additional side effects, lose their efficacy over time, and do not necessarily address all functional motor symptoms, current research has strongly argued for the inclusion of alternative therapies and physiotherapy alongside drug treatment (Giroux, 2007; Cutson et al. 1995; Yousefi et al., 2009).

2.5 Physiotherapy and Exercise Regimes for People with Parkinson's

Recent research has shown the multiple physical and psychological benefits that can come from participating in physical activity for people with Parkinson's (Tomlinson et al., 2012; Yousefi et al, 2009; Petzinger et al. 2010). Physiotherapy and exercise are no longer viewed as new ideas for the treatment of this condition with many neurologists, general physicians, and Parkinson's nurses encouraging patients to involve themselves in these activities. Organizations like 'Parkinson's UK', the leading organization in the United Kingdom for patients and their carers, often disseminate support materials to their members through small booklets and online resources. In their resource papers, Parkinson's UK encourage patients to take part in a wide range of activities depending on their interests and the kind of support they need. Some of these suggestions include occupational therapy, speech and language therapy, and physiotherapy (Parkinson's UK, 2013).

Clinical guidelines set by the National Institute for Health and Care Excellence (NICE) in 1999 state that these therapies should be made readily available and provided for people with Parkinson's. "NICE Parkinson's guidelines make recommendations to doctors, nurses, and other healthcare professionals on the most clinically effective and cost effective treatment they should provide for the care of people with Parkinson's" (Parkinson's UK, 2014:1). Organizations such as the Association of Physiotherapists in Parkinson's Disease Europe (APPDE) aim to initiate and support the transfer of knowledge between health care

professionals who work with Parkinson's to ensure best physiotherapy practice (APPDE, 2012).

Along with the three aforementioned therapies, Parkinson's UK has also listed these complementary therapies as potentially beneficial for this population based on recent research: Tai Chi, Yoga, Pilates, Acupuncture, Alexander Technique, the Feldenkrais method, Chiropractic work, Meditation, Music Therapy, Art Therapy, and the Bowen Technique (this list is not exhaustive and consists of many more therapies, including dance therapy).

A difficulty that has been recognized by Goodwin et al. (2008) is that many studies and review articles looking at the benefits of physiotherapy for people with Parkinson's tend to place other complementary therapies under the umbrella term of physiotherapy. This can make it difficult to "extract" information about particular modes of therapy and their specific effects and benefits for this population. For instance, Tomlinson et al. (2012:4) describe their view of physiotherapy in the quote below for their review article looking at the effectiveness of physiotherapy compared with no intervention:

"Physiotherapy encompasses a wide range of techniques, so we were inclusive in our definition of physiotherapy interventions (including those not delivered by a physiotherapist) with trials of general physiotherapy, exercise, treadmill training, cueing, dance, and martial arts included."

However, effort was made in this article to clearly distinguish and report results

from each different activity so that the reader can understand how one activity compares to another in all assessments. Even still, the authors were not able to conclude or evidence which form of activity was best. The conclusions saw that physiotherapy in general can provide short-term benefit, especially in relation to walking speed, balance, and disease severity (Tomlinson et al., 2012). The authors encourage readers to exercise caution with these conclusions as the trials included were not necessarily of high scientific rigor or quality. An additional critique shows that the studies reviewed for this article ranged in duration from three weeks to twelve months but nothing on a more longitudinal scale to understand longer-term benefits. It has therefore been suggested that future research focus on longitudinal intervention studies and follow up measures in an effort to gain more knowledge of the potential longer-term benefits.

There appears to still be debate about the potential mechanisms to explain how exercise and physical therapies are helping individuals with Parkinson's. One school of thought suggests that, "rehabilitative exercise interventions can have a neuro-protective effect and cause the brain to repair itself through neuro-plasticity" (Sharp and Hewitt, 2014:446; Hirsch and Farley, 2009). In order for positive adaptations to take place, it has been recommended that these five key principles of exercise and activity be considered:

"(a) intensive activity maximizes synaptic plasticity; (b) complex activities promote greater structural adaptation; (c) rewarding activities increase dopamine levels and promote learning/relearning; (d) dopaminergic neurons are highly responsive to exercise and inactivity;

(e) introduced early in the disease process, progression can be slowed”
(Goodwin et al, 2008: 631; Fox et al., 2006).

Keus et al. (2007) concluded that physical therapy in conjunction with pharmacological treatment improved quality of life for people with Parkinson's. In their article, the authors appear to use the term 'physical therapy' to encompass a wide range of active and passive exercises to improve range of motion, dexterity, balance, posture, gait, and physical capacity. Again, it appears there is some discrepancy in language as some may view the activities above as being one in the same as physiotherapy. Future research needs to work towards a common language to avoid confusion and allow researchers to be better able to compare results across the field. Keus et al. (2007) suggested that physical therapy is unlikely to influence the disease itself but rather it may help improve daily functioning by teaching and training movement strategies. The emphasis here appears to be on the learning of tools and strategies that may help individuals move with more ease and efficiency rather than changes to neuroplasticity or an increase in dopamine levels. However, it could be argued that the learning of new movement strategies is evidence of neuroplasticity and the ability of the nervous system to form new connections and pathways.

Other research suggests that exercise and physiotherapy sessions tailored to the individual's needs may help improve specific physical fitness components. In this case, improved fitness may help to relieve certain symptoms and thus aid activities of daily living. “There is a vast body of evidence that support the concept of task-specific training, which states that in order to improve a

particular task one should practice that same task” (Earhart, 2009:235). Thus, if an individual wants to improve fluidity of gait or their dynamic stability, they should practice walking and balance tasks that challenge these variables. There are many examples of task-specific training regimes in current exercise for Parkinson’s research. Schenkman et al. (1998) carried out a study looking at a ten-week exercise intervention for people living with Parkinson’s. Participants took part in three classes a week for ten weeks that focused on specific exercises to improve functional axial rotation, functional reach (see Appendix 1 for glossary of clinical scales and tests), and efficiency of moving from lying to standing. As the exercises were tailored specifically to these functional activities, the study found that participants in the exercise group improved on all of these measures and significantly improved functional axial rotation and functional reach in comparison to a control group. Protas et al. (2005) looked specifically at gait and step training for a small group of people with Parkinson’s. Participants took part in nine weeks of training (three times a week with each session lasting 60 minutes) and results showed a significant improvement in gait speed and cadence (see Appendix 1 for glossary of clinical scales and tests) with a substantial decrease in fall rates for the trained group. By tailoring these exercise interventions to strengthen specific physical fitness components and having participants train in ways that their body was not accustomed to, participants saw significant improvements.

For positive adaptations to occur, exercise must be performed regularly and with a certain level of progressive overload to avoid a physical plateau where the body becomes accustomed to the current level of work (King and Horak, 2009).

Unfortunately, compliance is often insufficient to achieve or maintain improvements in this population. Researchers are now trying to understand more about what motivates people to be physically active and continue therapeutic interventions (Sharp and Hewitt, 2014).

Many studies suggest that social interaction can be a key motivator for individuals to maintain physical activity levels. In a study conducted by Dereli and Yaliman (2010) a physiotherapist-supervised exercise programme was compared to a self-supervised exercise programme. The physiotherapist-supervised exercise programme proved to be more effective at improving activities of daily living, mental and motor functioning, as well as overall quality of life than the home-based, self-supervised programme. This result indicates that physical activity carried out with other people, either with a supervisor or in a supervised group setting, has the potential to be more effective than carrying out prescribed exercises at home on one's own.

There are many possible explanations for these results, some of which the authors mention in their article. Certainly there may be an element of motivation to do well when being watched or supervised during an activity. Often times when carrying out physical activity with others in the room there will be conversation, possibly even external cueing and discussion of strategies that may help to explain why the advancements here may be more significant than that seen in home-based programmes. However, it is important to note that Dereli and Yaliman (2010) make clear that the self-supervised exercise group in their study still improved in quality of life as well as motor symptoms and functional status.

In contrast to the above findings, Lun et al. (2005) found that a self-supervised exercise programme- had a similar level of effectiveness as the physiotherapist-supervised exercise programme for people with Parkinson's. Results from the study demonstrated a similar level of improvement in motor symptoms as measured through the Unified Parkinson's Disease Rating Scale (UPDRS). The UPDRS has been included in multiple 'dance for Parkinson's' research studies, some of which are discussed in this literature review. The scale consists of four parts that look at severity of non-motor symptoms, activities of daily living, severity of motor symptoms, and side effects from common Parkinson's medications such as dyskinesia (Goetz et al., 2007) (see Chapter Six for further information regarding the UPDRS). This study suggests that it may be possible to reach the same level of benefit so long as the participants are motivated to carry out the exercise programme on their own.

O'Brien, Dodd, and Bilney carried out a study in 2008 on the qualitative analysis of a progressive resistance exercise programme for people with Parkinson's. Semi-structured interviews were carried out with participants who had participated in a ten-week progressive, resistance strength-training programme. The authors found that the social aspects of the programme and being around other people living with the same condition were stronger motivators to continue with the programme than motivation to increase muscle strength. The authors note that this finding is consistent with previous research showing social interaction and support is associated with better exercise adherence (O'Brien et al., 2008).

Studies focusing on dance for people with Parkinson's have shown participants are motivated to attend these classes regularly with high levels of compliance and low dropout rates (Earhart, 2009). Dance is multi-dimensional activity that can encourage the engagement of auditory, visual, and kinesthetic senses. Depending on the form taken, different kinds of dancing can also allow for social interaction, physical and mental challenge, creativity, and expression (Sharp and Hewitt, 2014). Studies in this field to date have worked with a variety of dance forms including a range of ballroom styles (tango, waltz, foxtrot), creative-based work, contemporary, ballet, Irish-set dancing, and contact improvisation. Classes are done in a group setting and exercises are tailored/modified to meet the individuals' needs. Verbal cues from the instructor and auditory cues from music may prove extremely beneficial in helping people improve fluency of movement and reaction time (Earhart, 2009). Furthermore, research suggests that moving to music may elicit physiological pleasure sensations related to reward and emotions, which subsequently may increase compliance and motivation to attend the classes (Blood and Zatorre, 2001; Lim et al., 2011).

Dance also incorporates the practice of many functional movements that people with Parkinson's may have difficulty with in their everyday lives. Functional movements often seen within a dance class include rotation in the trunk, walking in different directions and at varying speeds, shifting weight effectively to maintain stability, and mobilizing the upper and lower limbs in relation to the trunk (Earhart, 2009). Task-specific training like that seen in dance may help to improve activities of daily living and thus impact on participation in society. The argument for the inclusion of dance as an alternative therapy to be carried out

alongside the prescribed drug therapy is gaining much strength as a result of the benefits described above.

2.6 Dance for Parkinson's: The Strengths and Weaknesses of Current Research

Research into dance as a form of alternative therapy for people with Parkinson's has sparked the interest of dance artists and academics in recent years. Although dance movement therapy has proven to be a beneficial component of rehabilitation for other neurological disorders, such as traumatic brain injury and autism, since the 1970's (Adler, 1974; Berrol and Katz, 1985) the first study of dance movement therapy for people with Parkinson's was only reported by Westbrook and McKibben in 1989. It was shown that dance therapy helped to improve initiation of movements (i.e. reaction time) more effectively than the exercise class. An improved mood was also apparent in the dance therapy group, though these results were not statistically significant (Westbrook and McKibben, 1989). However, there is a need to make clear the distinction between the focus on therapeutic benefit that is often aimed for in dance movement therapy sessions versus the aim of experiencing and learning an art form that is often provided in a dance for Parkinson's class. (McGill, Houston, and Lee, 2014).

The American Dance Therapy Association (ADTA) defines dance movement therapy as "the psychotherapeutic use of movement to further the emotional, cognitive, physical and social integration of the individual" (ADTA, 2009-2015). In this case the participants engage with dance as a therapeutic tool or treatment.

On the other hand, dance for Parkinson's groups may view dance as being an alternative form of physical activity and exercise. They tend to place emphasis on learning about dance as an artistic practice and often times will focus on particular styles of dance such as contemporary, ballet, contact improvisation, or ballroom. The aim is not necessarily to focus on the self in a therapeutic context but rather to learn about dance as a creative, social, and artistic practice that may also help alleviate symptoms and improve quality of life (McGill, Houston, and Lee, 2014). In this context, although research that surrounds dance for Parkinson's classes often looks at the therapeutic benefit, participants are not necessarily engaging with dance solely for this purpose.

From 2007 to present we have seen an influx in research studies focusing on dance for Parkinson's with a wide range of protocols and dance forms. While many of these studies do not necessarily distinguish between therapy and art as discussed in the above paragraph, they do place a strong emphasis on understanding how dance can improve Parkinson's symptoms. In 2007 Hackney et al. found that tango dance helped to improve balance as evidenced by improved scores in the Berg Balance Scale (BBS) for a group of people with Parkinson's (see Chapter Four for further information regarding the BBS). Participants in this study were dancing twice weekly for a period of ten weeks. In comparison, the exercise group in this study did not see significant improvements in BBS scores. Furthermore, it appeared that the level of interest differed between the dancing and exercise group with many of the tango participants continuing to participate in classes after the project and the exercise group discontinuing their participation (Hackney et al., 2007).

In a study that compared American ballroom and Argentine tango, Hackney and Earhart (2009a) found that both dancing groups improved significantly on the BBS, six minute walk distance, and backward stride length (see Appendix 1 for glossary of clinical scales and tests) whereas the control group, who had no intervention, did not improve on these measures. It is interesting to note that although forward stride length and walking velocity (gait speed) were measured in Hackney and Earhart's study (2009a), there were no significant improvements here. The authors do not discuss this relationship between forward and backward walking in detail. It would be useful to understand more clearly how meaningful a change in backward stride length is when the forward stride length has not improved to the same extent. Other gait variables such as single support time (see Appendix 1 for glossary of clinical scales and tests), a variable that may provide an indication of dynamic stability, showed improvement but this was slight and not as marked as the differences seen in other measurements. The researchers also noted that the tango group improved the same and in some cases more than the ballroom group, thus concluding that tango may address motor deficits seen in Parkinson's more effectively than the waltz or foxtrot. An exit questionnaire was also given to both dancing groups to assess the level of enjoyment and participant perception of changes in mood and other physical variables outside of the dance class. Results showed that the participants enjoyed the classes, noticed improvements in their balance, walking and coordination, and would continue to participate in classes if possible (Hackney and Earhart, 2009a).

More recently we have seen the inclusion of other dance forms in this area of research. In 2010 Marchant, Sylvester, and Earhart looked into the effects of a short duration, high intensity contact improvisation workshop that took place across a two-week period. Eleven participants with Parkinson's took part in ten classes each one and a half hours in length. Disease severity, balance, functional mobility, and gait were assessed one week before and after the intervention with use of clinical rating scales and biomechanical measures. Significant improvements were once again seen in the BBS as well as part three of the UPDRS, otherwise known as the motor subscale. An improved score in part three of the UPDRS indicates that the dance intervention helped to alleviate physical Parkinson's symptoms. The percentage of gait cycle spent in stance phase decreased significantly in Marchant et al.'s 2010 study while time spent in swing phase increased significantly possibly indicating improved dynamic stability. Functional reach and tandem stance (see Appendix 1 for glossary of clinical scales and tests) showed non-significant improvements (Marchant et al., 2010).

Heiberger et al. (2011) noticed a gap in this area of research in that few studies had looked at the beneficial effects immediately after a dance session. As a result these authors looked at short-term effects on motor control for people with Parkinson's as well as longer-term effects on quality of life after eight months of participation in weekly dance classes. Results showed significant short-term improvements directly after class for the UDPRS motor subscale, in particular measures of rigidity and hand movements. However, no significant improvements were seen in balance and gait directly after class (as measured by

the Semitandem test and the Timed Up and Go (TUG) measurement) (see Appendix 1 for glossary of clinical scales and tests). Authors made note of this surprising result given past research consistently finding positive results for dance improving balance and gait in people with Parkinson's. They suggested that this lack of improvement could be due to the fact that participants are often fatigued after class and this fatigue may mask the improvement. Furthermore, they proposed that balance and gait may only be seen to develop on a long-term scale and cannot be clearly observed on a short-term scale (Heiberger et al., 2011). However, it is interesting to note that these authors chose to assess balance using different measurements than that seen in previous studies that rely more heavily on the BBS to assess this variable. Additionally, this study looked at the effects of a weekly dance class whereas other studies tend to have a higher frequency of dance classes per week.

Similar to that seen when discussing exercise for people with Parkinson's, there is still much debate about the underlying neural mechanisms to explain the positive adaptations seen after taking part in dance. Some studies suggest that regions of the brain that are impaired in people with Parkinson's, specifically the basal ganglia, are activated when taking part in dance (Brown et al. 2006). Other research suggests that the basal ganglia and impaired parts of the brain can be bypassed completely in dance as a result of auditory cues such as music and metered beats allowing for alternative neural pathways to be created and used (Cunnington et al., 1995). Participants may enter the dance class displaying a variety of Parkinson symptoms and soon find that they are moving freely and in a coordinated fashion once the music begins to play. Past research has shown

that rhythmic auditory cues can have a substantial impact on the fluidity and coordination of gait patterns for people with Parkinson's (McIntosh, et al., 1997; de Dreu et al, 2012). Further research is needed to understand more clearly how dance is affecting the neuromuscular system.

Depending on the style, dance can offer a variety of physical and mental challenges that may help to improve strength, flexibility, and coordination while exercising the brain and developing cognitive skills. Dance often requires people to multitask and move different parts of the body at the same time whilst also having to anticipate the next action in a sequence of movements. Moreover, participants are often asked to remember and perform movement sequences from the previous class, some of which may last for up to several minutes. These elements of the dance class provide a mental challenge that is often noted by participants after the sessions. Throughout the course of a dance class participants may be seen walking/marching around the space, an action that can help strengthen muscles in the ankles, legs, hips, and core while also improving coordination of the arms and legs in motion. Participants are often asked to lift their arms overhead or rotate/twist in the trunk, both of which aid flexibility and can help to relieve rigidity. As with any form of exercise, if this work is done often enough and with appropriate levels of physiological overload, elements of physical fitness including agility, coordination, and balance may improve thus aiding activities of daily living.

2.7 Critique of Recent ‘Dance for Parkinson’s’ Research and Their Methodologies

Upon reviewing these studies it is clear that there are developing trends with respect to choice of variables to be assessed and overall methodologies. As Parkinson’s can have detrimental affects on smoothness of gait, stability, rigidity, coordination, and posture (McAuley, 2003), studies in dance for people with Parkinson’s tend to focus on these variables to see if dance can help alleviate some of these common symptoms. Moreover, the specific measurements used to assess these variables are often the same. For example, the TUG measurement (Podsiadlo and Richardson, 1991), the BBS (Berg et al., 1989), the Sit to Stand test (Bohannon, 1995), the Functional Reach test (Duncan et al., 1990), and more recently the Fullerton Advanced Balance (FAB) Scale (Rose et al., 2006) are all validated rating scales commonly used in dance for Parkinson’s research (see Appendix 1 for glossary of clinical scales and tests). A few studies in this field of research have also used biomechanical measures to assess gait variables with use of the GAITrite walkway system (Hackney and Earhart, 2009a).

Many of the studies to date in this field tend to rely heavily on the results seen from clinical rating scales, in particular the BBS, when making conclusions about how dance may affect balance and functional mobility. While the aforementioned rating scales including the BBS are validated measures that have shown to be highly correlated to other clinical rating scales (Berg et al., 1992), there have been few studies that discuss biomechanical gait measures as a means of assessing dynamic stability, despite many studies including the biomechanical

assessment of gait variables. Furthermore, stumbles and falls often happen when in motion. Thus it seems important to understand stability in motion as opposed to focusing so heavily on balance in quiet stance as is seen in the BBS (i.e. balancing on one leg for a period of time or balancing on two feet with eyes closed).

The idea of varying methods of assessment warrants further discussion, as it seems that research may be biasing our understanding of how dance may affect balance if studies are consistently using the same measures to assess this variable. It is necessary to vary our measures and compare other means of assessing balance with those currently used to truly substantiate the conclusions we are making about dance having a significant positive impact on balance. That said one of the potential problems seen when using new techniques to assess balance is that the results will not necessarily be comparable to that seen in other studies. However, if both assessments are validated and reliable in their own right, then the research should be showing a reliable result and therefore the findings should be comparable to a certain extent.

In a recent study, Hackney et al. (2007) examined the effects of Argentine Tango in comparison to exercise for those with and without Parkinson's. This particular study did not use the Berg Balance Scale or the Fullerton Advanced Balance Scale but instead looked at the One Leg Stance, the Functional Reach Test, the Activities-Specific Balance Confidence Scale, and the Falls Efficacy Scale. The Parkinson's tango group was the only group to improve on all 4 measures in this study. However, the Parkinson's exercise group also improved on both the One

Leg Stance Test and the Functional Reach test, with the exercise group showing greater improvements than the tango group on the One Leg Stance. Walking velocity was also assessed in this study and the authors found that all groups, including the controls, improved slightly on this measure.

Hackney, Kantorovich, and Earhart then published a separate article in the same year (2007) that looked more closely at the comparison between the Tango and exercise classes for people with Parkinson's and in this article the BBS was used. The study found significant positive improvements in the BBS for the tango group and not for the exercise group. It is interesting to note that a more positive significant result seems to occur with the BBS in comparison to the other measures used across the two studies including the One Leg Stance, the Functional Reach, and walking velocity (which have all been used in previous research to assess balance in people with Parkinson's) (Chomiak et al., 2015; Behrman et al., 2002; Nemanich et al., 2013).

Houston and McGill (2013) assessed changes to balance using the FAB scale in their study looking at the effects of weekly ballet sessions for people with Parkinson's across a twelve-week period. The authors found a significant improvement in balance scores from pre to post measurement however they note that "due to the small sample size, statistical power of these results is not sufficient to conclude statistical significance or to generalize these results to the wider population" (Houston and McGill, 2013:112). Upon analysing their results the authors also make note of an interesting observation and state that to even attempt the tasks involved in this clinical rating scale, there is a certain amount of

trust and confidence needed from the participant. They noted that by the end of the study, participants appeared to be more confident to try movement out and attempt tasks that they may have avoided previously. Balance confidence is rarely assessed in dance for Parkinson's research and may provide additional insight into why balance results are improving on clinical rating scales post intervention.

In their systematic review of research focusing on dance as an appropriate and beneficial activity for people with Parkinson's, Sharp and Hewitt (2014) argue that much of the research emphasizes tango dance in particular and its potential benefit for this population. These authors suggest future research should compare different forms of dance to determine whether tango itself conveys benefits over and above other forms of dance outside the ballroom realm. As discussed above, a recent study by Houston and McGill (2013) looked at the beneficial effects of a ballet-based dance class for people with Parkinson's. This is the first study of its kind in the dance for Parkinson's field to focus on ballet specifically. Houston and McGill (2013) state that ballet emphasizes "posture, body alignment and projection of eye focus and limb extension, as well as whole-body coordination. It is a form of dance that can challenge one's strength and stability and also encourages a wide range of movement qualities and dynamics," (pp. 105). It is therefore surprising that research has neglected to look more closely at how ballet can help this particular population given the potential benefits.

As was discussed above, although studies have looked at various dance forms including contact improvisation, creative dance, and contemporary dance forms,

these studies tend to not compare the styles against one another. Furthermore, the recommendation for studies to focus on longer-term benefits has been argued in multiple papers to date (Sharp and Hewitt, 2014; Earhart, 2009). While most studies in the field have ranged from two weeks to 12 months, recent research has called for longer duration interventions that may show greater improvements in mobility and balance (Shanahan et al., 2015).

A recent study by Duncan and Earhart (2014) looked at the effects of community-based tango dance on people with Parkinson's over a two-year period. The authors state that the study is believed to be one of the longest-duration studies to examine the effects of exercise on Parkinson's, and is also one of the longest-duration studies focusing on dance for this group of people. Duncan and Earhart found a significant group-by-time interaction for motor severity as measured using part three of the UPDRS with the dancing group showing lower (better) results than the controls at 12 and 24 months. However, it is important to note the possible difficulties with attrition rates when trying to achieve longer duration interventions, especially as symptoms become more severe and travelling to and from the dance studio becomes more difficult for the participant. The study described above by Duncan and Earhart (2014) looked at only 10 participants in total (five in the tango group and five in the control group).

Shanahan et al. (2015) argue for larger sample sizes to allow for better generalization of results to the wider Parkinson's population. Again, this particular recommendation has been advised by multiple researchers and is

important in presenting meaningful statistical results (Earhart, 2009). However, it is important to note that many studies have repeated measures of specific variables within the dance context to substantiate conclusions drawn about potential benefits. While this paper argues that it would also be useful to vary the assessment methods to substantiate conclusions drawn about potential changes, the repetition of studies looking at this particular area do help to substantiate conclusions drawn about the benefits of dance when group sizes are small.

There is a lack of discussion in studies focusing on dance for people with Parkinson's on specific guidelines for frequency, intensity, timing (duration), and type of dance that will allow for best results. In the exercise and fitness sector this is referred to as the FITT principle and is something that can help guide the participant, instructor, and/or researcher in creating a programme that will allow for the best possible outcome (Power and Clifford, 2013). This point will be discussed later in the discussion section of this dissertation, however Shanahan et al. (2015) also concur with this argument and the subsequent need for clearer guidelines.

Dance for Parkinson's studies to date have assessed not only the change in physical, and sometimes mental, functioning of the individuals taking part in dance sessions, but also changes to their overall quality of life and wellbeing. However, the physical changes tend to be discussed more prominently in many papers and are highlighted with more strength in the abstracts. Nevertheless, health-related quality of life scales have been included in an effort to understand better the impact that dance may have on the person and their activities and

lifestyle outside of the dance context. One of the most common measurements used to assess this in recent dance for Parkinson's work is the 39-item Parkinson's Disease Questionnaire (PDQ-39), a summary index which indicates global impact of Parkinson's on health status (Bushnell and Martin, 1999). In a recent study comparing Irish dancing and physiotherapy interventions, quality of life was assessed using the PDQ-39. For both the Irish Dancing and Physiotherapy groups, PDQ-39 scores showed a similar amount of improvement signifying that participants felt that their Parkinson's symptoms were not impacting as heavily on their health and wellbeing after both interventions (Volpe et al. 2013).

Heiberger et al. (2011) utilized the Quality of Life Scale (Oregon Health and Science University) in their study looking at short and long term effects of dance for people with Parkinson's. The authors found that the items that changed for the better as a result of taking part in the dance classes include "recreation, socializing, relationships, and helping and encouraging others" (Heiberger et al., 2011:10). Furthermore seven out of eleven participants reported positive impact on everyday life after each dance class with some reporting this effect lasting up to a few days after the event.

Hackney and Earhart published results on a study that compared Tango, Waltz/Foxtrot, Tai Chi and no intervention on health-related quality of life as measured via the PDQ-39. This particular study was separated into two articles, one that focused specifically on physical changes and one that focused on improvements to health-related quality of life (Hackney and Earhart, 2009a;

Hackney and Earhart, 2009b). The tango group showed significant improvements in the ‘mobility’ and ‘social support’ components of the scale, as well as the PDQ-39 Summary Index, which indicates the global impact of Parkinson’s on health status. No significant changes in health-related quality of life were noted in the Waltz/Foxtrot, Tai chi, or No intervention groups.

It is important to note recent arguments made by Den Ouden et al. (2011) that quality of life may be better measured via focus group discussions or interviews that take into consideration the person’s own perception of health and wellbeing rather than relying on structured quantitative methods. This is due to the fact that questionnaires often try to fit participants into set categories even though they may not always be applicable to the individuals being tested. A more individual approach may therefore prove to be more useful and provide further insight into changes in quality of life.

While measures of health-related quality of life have been included in previous dance for Parkinson’s studies, there are very few that place equal emphasis on these findings alongside physical changes as seen in biomechanical measures and clinical rating scales. Furthermore, there is a general lack of understanding in how variables of health-related quality of life correlate to changes seen in physical and mental functioning. There is a need to triangulate this information to better understand the impact that dance may have on people living with Parkinson’s.

The following section aims to address the need to understand how dance may affect people on a variety of levels and proposes a new framework for dance for Parkinson's research that may help to allow for triangulation of qualitative and quantitative results.

2.8 Dance for Parkinson's: A New Framework for Research on its Physical, Mental, Emotional, and Social Benefits ¹

There is a need for a framework that allows for the study and analysis of the dancing experience for people with Parkinson's on a variety of levels including physically, mentally, emotionally, and socially. With such a framework it would be possible to triangulate the information and determine relationships between variables thus helping researchers to better understand how dance is affecting the individual and/or group. Through this kind of analysis we can draw stronger conclusions, which are more meaningful to people with Parkinson's.

Individual differences must also be recognized and considered within the analysis. Parkinson's is a neurodegenerative disease that affects each individual in a very different way (Pedrosa and Timmermann, 2013). Results will depend on how the participants engage with the movement material, how their Parkinson's is affecting them at any given time, issues outside of the dance studio such as family health, and a variety of other contextual factors. It is important to not

¹ The material in this section appeared as a peer-reviewed article in *Complementary Therapies in Medicine* (McGill A, Houston S, Lee R. Dance for Parkinson's: A new framework for research on its physical, mental, emotional, and social benefits. *Complementary Therapies in Medicine*. 2014;22(3):426-432)

neglect these components but rather include them in our understanding of the outcomes. Houston (2011) argued for a person-centred approach within dance for Parkinson's research whereby the need to look at the person experiencing the dance is prioritized rather than solely looking at how dance may alleviate symptoms. Houston argues that this approach puts the participants' experiences, thoughts, feelings, and emotions about dancing at the forefront and concerns itself with the 'why' and 'how' dance is experienced rather than causal effects (Houston, 2011). The present study proposes that an understanding and appreciation of the individual experiencing the dancing as well as the causal effects of that dance experience are both important to our understanding of how dance can help people cope better with their Parkinson's symptoms.

The aim of this section is to propose a framework for dance for Parkinson's research that will enable analysis of the dancing experience from multiple perspectives with triangulation of qualitative and quantitative information. This framework is underpinned by a person-centred approach that does not neglect the individual experiencing the dance classes but rather includes personal contextual factors within the wider analysis. It is necessary for the framework to be internationally recognized and acceptable to researchers in a wide range of fields including biomedical and social scientists as well as arts and humanities scholars.

2.8.1 World Health Organization's Definition of Disability

In 2002 the World Health Organisation (WHO) officially published the International Classification of Functioning, Disability, and Health (ICF) stating the following:

“It (the ICF) is a classification of health and health-related domains -- domains that help us to describe changes in body function and structure, what a person with a health condition can do in a standard environment (their level of capacity), as well as what they actually do in their usual environment (their level of performance). These domains are classified from body, individual and societal perspectives by means of two lists: a list of body functions and structure, and a list of domains of activity and participation,” (WHO, 2002:2).

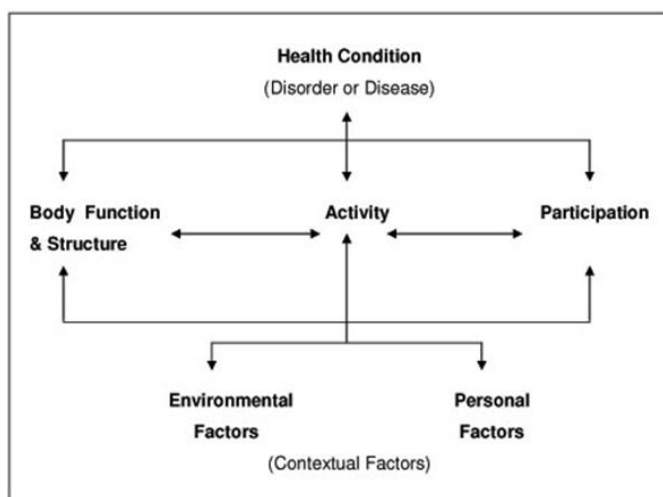
It is hoped that the ICF can be utilized in a variety of different situations some of which include policy development, economic analyses, clinical analyses, and research. Within the research context, it can provide “a scientific tool for consistent, internationally comparable information about the experience of health and disability” (WHO, 2002:5). This tool, or framework, is ideal for interdisciplinary research that wishes to not only understand the causal effects of impairments on everyday life but also consider the contextual factors that may influence participation.

Recent literature indicates a strong debate that has taken place with respect to defining disability and its various components. Earlier definitions developed by Wood in 1980 for the World Health Organization (WHO) have been criticized for seemingly taking a medical standpoint that does not fully recognize social

and political constructs that may not allow persons with impairments to participate in society (Thomas, 2007; Oliver, 1990). The medical model assumes the physical or mental impairment is the main reason why the individual cannot partake in activities. Prior to Wood developing this definition in 1980, the social model was developing in response to the medical way of thinking. The social model is based on the idea that disability is a form of social oppression with the exclusionary behaviour of society being the main issue and not the impairment itself (Oliver, 1990; Abberley, 1987). However, this model has also been criticized due to the fact that it seems to neglect the body and the idea that the impairment is something experienced within the body (Houston, 2011).

With regards to the ICF, the WHO is bringing the medical and social models together with the view that neither model on its own is adequate but both are valid and need to be considered. As a result, this new classification builds upon George Engel's concept of the biopsychosocial model (Engel, 1977; Engel, 1980), and presents a framework that does not neglect the body or the social/political constructs but rather includes them both in our understanding of disability (Engel, 1977). The following diagram taken from a WHO report written in 2002 clearly depicts the inclusion and interaction between health conditions and contextual factors. It is particularly interesting to note that their description of contextual factors not only considers the environmental factors that may influence participation but also personal factors including "gender, age, coping styles, social background, education, profession, past and current experience, overall behaviour pattern, character, and other factors that influence how disability is experienced by the individual" (WHO, 2002:10).

Figure 1.1 A Representation of the ICF Model



(WHO, 2002:9)

It is important to note that the first domain of the ICF entitled “Body Function and Structure” also includes psychological functioning within its categorical definition (WHO, 2002). Throughout the ICF manual and other WHO reports one may see this domain discussed in a way that seems to refer only to the physical body. However, it is explained within the ICF manual that although not explicitly stated in the title, psychological functions are also to be considered within this domain.

In response to Houston’s article in 2011, the present study calls for an approach that recognizes the importance of the dancing person and their unique experience rather than merely looking at the individual as an impaired body that needs correcting. The World Health Organization’s ICF, in a similar fashion, presents a biopsychosocial model with a view that it is not sufficient to look solely at the impaired body but rather that it is also necessary to consider personal contextual factors that may influence one’s participation in activities and life situations

(WHO, 2001). By combining the two ideas there is an approach to dance for Parkinson's research that does not neglect the body or mind but also takes into consideration the context in which that person lives and possible changes to activities and everyday life. Given the similar aims and objectives described above this thesis proposes the use of the ICF as a framework for dance for Parkinson's research.

The use of the ICF framework to capture the full spectrum of health and disability is not a new concept in exercise for Parkinson's research and has been utilized many times (Dibble et al., 2009; Dibble et al., 2010; Ellis et al., 2011). The development of such work can be seen in studies like Schenkman and Butler (1989) who proposed a more holistic model to evaluating and treating people with neurological conditions. Although the ICF framework was not specifically utilized in their paper, the basic concept of looking at the interrelationships between pathology, impairments, and subsequent affect on emotional, social, physical and mental health were made apparent.

One could argue that this more holistic approach forms the fundamental basis and structure for dance movement therapy. Referring back to the ADTA, dance movement therapy encourages individuals to engage with movement to further the emotional, cognitive, physical and social aspects of the self, thereby already incorporating a person-centred approach in its function (ADTA, 2009-2015). Goodill (2005) developed her own framework to assess changes to health as a result of dance movement therapy sessions, much of which stemmed from the biopsychosocial model of health and illness, similar foundations to what the ICF

was built upon.

As mentioned earlier, although some researchers have chosen to discuss enjoyment levels, community engagement, and other social/emotional factors, these changes tend to be reported only after emphasizing changes to physical symptoms. To my knowledge there are no dance for Parkinson's studies that utilize a clear framework placing equal emphasis on the various domains as seen within the ICF. In addition, there appears to be no attempt in dance for Parkinson's research to utilize frameworks or models seen in the medical and social science fields with the aim of sharing knowledge of the potential benefits with a wider audience.

2.8.2 Structuring Dance for Parkinson's Research using the ICF Framework

1. Body Functions and Structure

Much of the research to date has focused on changes in symptoms and disease severity across the time of a dance intervention. As mentioned at the beginning of this chapter, common Parkinson's symptoms include instability, a stooped posture, festination, bradykinesia, rigidity, and tremor. People with Parkinson's may experience feelings of depression and loneliness as a result of the difficulties they face and may avoid participating in activities due to low self-esteem and anxiety.

Sections 2.6 and 2.7 of this chapter outline various clinical scales and biomechanical measurements that have been used to assess changes to posture,

gait, rigidity, and stability in recent research (Heiberger et al., 2011; Hackney and Earhart, 2010a). For instance, the aforementioned Unified Parkinson's Disease Rating Scale (UPDRS) and the Berg Balance Scale (BBS) are commonly used to assess changes to physical symptoms across a dance intervention. Furthermore, this chapter has also outlined biomechanical measures of gait such as step length and walking speed that are often incorporated in dance for Parkinson's studies (Marchant et al., 2010). A focus on assessing changes to physical and mental symptoms demonstrates a focus on function or structure of the body and therefore could be included within the first level of the ICF framework (changes in body function and structure) (WHO, 2001; 2002).

2. Daily Activities

Within the ICF model "Activity" is defined as the following: "In the context of health experience, Activity is the execution of a task or action by an individual. Activity limitations are defined as difficulties an individual may have in executing activities" (WHO, 2001:212-213).

Research has recommended that the following key components should be included within an exercise program for people with Parkinson's to help individuals manage their Parkinson's in everyday activities: "cueing strategies to improve gait (visual or auditory), cognitive movement strategies to improve transfers, exercises to improve balance, and training of joint mobility and muscle power to improve physical capacity" (Keus et al., 2007:451). Dance can address all of these recommended areas and thus it appears that this may be a beneficial therapy for the management of Parkinson's (Earhart, 2009). Through auditory

(rhythmical), verbal, and visual cueing, individuals may be able to learn valuable techniques to help them carry out everyday activities in a safe and efficient way. As discussed previously, dance also involves elements of multitasking, something that can be particularly difficult for an individual with Parkinson's.

When reflecting upon the kinds of questions a dance for Parkinson's researcher may look at with respect to assessing activity limitations, it is apparent that many of the questionnaires used in current research including the UPDRS (Goetz et al., 2007), and the 39-item Parkinson's Disease Questionnaire (PDQ-39) (Peto et al., 1995), address this particular area of concern. Part two of the UPDRS (motor experiences of daily living) is a questionnaire to be filled out by the participant and looks at questions relating to the ease of carrying out everyday activities on one's own. Some activities that are addressed in this section include eating, dressing, handwriting, and maintaining hygiene (Goetz et al., 2007).

3. Level of Participation

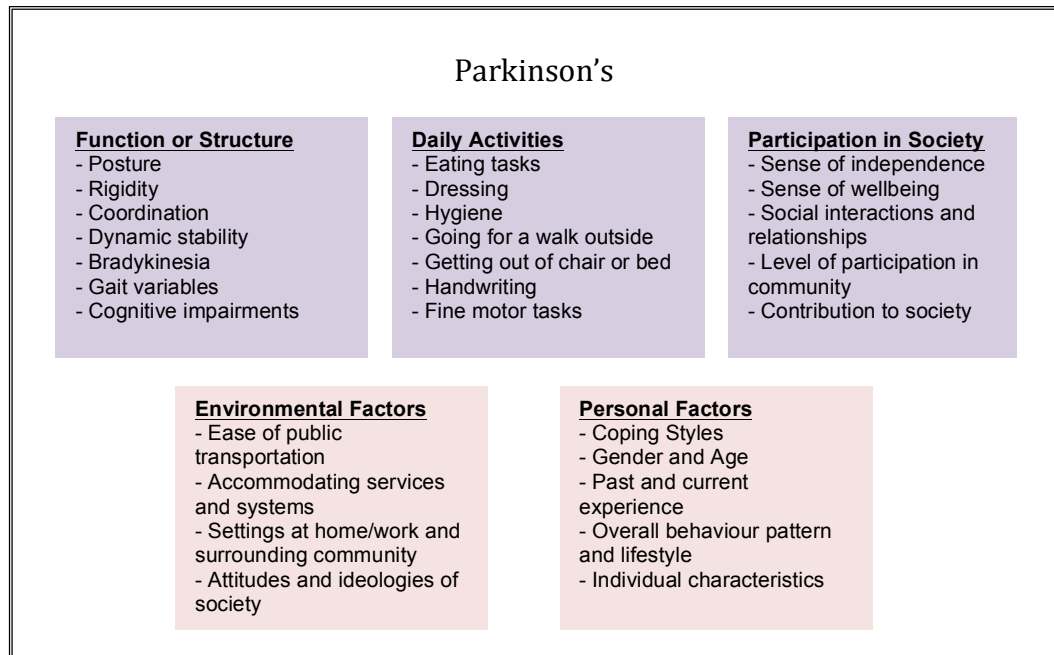
In the 2002 WHO report, 'participation' is described as involvement in life situations and 'participation restriction' is described as problems an individual may experience in involvement in life situations. Areas that relate to the participation domain include relationships/social interactions, involvement in the surrounding community, ability to contribute to society such as engaging in voluntary work or political activism, and having a sense of independence and wellbeing (WHO, 2001; 2002). To my knowledge, Foster et al. (2013) were the first to assess changes to activity participation as a result of a dance-based intervention using the Activity Sort Card (see Chapter Seven for further

information regarding this study). Other dance for Parkinson's studies try to address ideas relating to participation in society via exit questionnaires, quality of life questionnaires or semi-structured interviews (Heiberger et al. 2011; Hackney and Earhart, 2010a). However, as argued earlier in this chapter, many studies neglect to triangulate this information with other physical measures to substantiate conclusions drawn about the measured affect that dance is having on participants.

Within dance for Parkinson's research participation may be examined as both a function and an achievement for the participants. Those taking part in the dance sessions are in fact already participating in a social activity. However recent research has also noted the potential for an increase in participation of other activities outside of the dance studio as a result of taking part in cultural programmes such as dance (Heiberger et al., 2011; Cohen et al., 2006; Foster et al., 2013). As mentioned previously, those with Parkinson's may isolate themselves avoiding participation in other activities (Cummings, 1992). An activity such as dance that encourages engagement and socializing with other people may prove to be a trigger for change in participation levels as defined by the WHO.

The diagram below illustrates how specific variables described above may fit into the ICF framework. These variables may then be assessed across the duration of the dancing period to gain a better understanding of changes taking place. These lists are not exhaustive and many other variables may be included.

Figure 1.2 Dance for Parkinson's Research with use of the ICF Framework



2.8.3 Applying the ICF Framework in Research: Overlapping

Boundaries and Triangulation of Results

Jette (2006) argues that in order for the ICF to achieve its aim of being a scientific basis for understanding health and health-related states, it is critical that the three domains of function, activity, and participation are made clearly distinct from one another so that they are each measurable in their own right. He notes that one of the main criticisms of the original International Classification of Impairment, Disability, and Handicap (ICIDH) and a point that the ICF manual reconfirms is the difficulty in distinguishing between the domains of Activity and Participation (Jette, 2006). Although Jette and many others argue for a framework that has clearly distinct domains, it appears that in the context of dance for Parkinson's research these boundaries may exist but also overlap with

each other. Certainly there are factors such as gait and balance that fall into more than one domain (i.e. walking is a function of the body but can also be viewed as an everyday activity). Similarly, active homemaking and maintenance may be viewed as an everyday activity but also as an important part of one's sense of independence and participation within society. This overlap need not be a problem but rather a strength of the proposed framework that will allow researchers to look at variables such as walking from multiple different perspectives. Consequently the overlapping boundaries may provide the researcher with more knowledge and understanding of how dance may influence these variables.

Through analysing the situation from multiple different perspectives using the ICF framework one may be able to not only state what happened in the study but also attempt to explain why and how the results formed in the way that they did (Houston and McGill, 2013). Understanding the “why” and “how” behind the results can help us draw stronger, more meaningful conclusions that will help research in this field to progress in the longer term. If we do not concern ourselves with these questions then we as researchers run the risk of drawing conclusions too early about things that we do not fully understand.

2.9 Chapter Summary

Recent research has shown dance to be a successful form of alternative therapy for people living with Parkinson's. Improvements in balance and gait variables have been noted with numerous studies concluding that dance can help to

improve functional mobility for people with Parkinson's. However, there is a lack of research that aims to further understand how these physical changes are impacting upon activities of daily living (ADL) and level of participation in society for these individuals. Furthermore, there is a general lack of understanding in how variables of health-related quality of life correlate to changes in physical and mental functioning. Through an understanding of the relationships between these variables we may be better able to discuss how and why dance could be beneficial and valued by this group of people.

This thesis proposes the use of the World Health Organization's International Classification of Functioning, Disability, and Health (ICF) as a framework for dance for Parkinson's research. The ICF presents a biopsychosocial model for disability that takes into consideration the impaired body and/or mind as well as personal and environmental contextual factors that may influence how an individual participates in everyday activities and life situations. This model is ideal for dance for Parkinson's research that aims to examine not only how dance may affect clinical signs and symptoms but also understand how dance may affect participation in daily activities and life experiences.

It is necessary to use a model that is recognized across multiple professional fields including the medical, clinical, and social science sectors. By using an internationally recognized model this research can be better understood, appreciated, and analysed by individuals who see Parkinson's patients on a regular basis and who provide suggestions to help them cope better with their symptoms.

Chapter Three

Methodology

3.1 Ontological and Epistemological Approaches

Historically researchers have tended towards particular paradigms or ways of knowing such as positivism or constructivism, and these paradigms have led to employing certain methodological approaches (Guba and Lincoln, 1994). Positivism presupposes that there is an objective reality that can be explained by data collected through experimental research designs. The aim is to create distance between the subjective biases of the research and the objective reality being studied. Approaches born out of this paradigm rely heavily on experimental data collection (often quantitative in nature) and interpretation of results leads to valid and reliable conclusions that can be generalized outside the context of the study (Collins, 2011; Rothe, 2000). Constructivism assumes that there are multiple ways of knowing and understanding the world. This philosophical standpoint emphasizes the subjective relationship between the researcher and participants and the co-construction of meaning that is born out of that relationship (Mills et al., 2006).

As proposed in the literature review chapter, this PhD will use a mixed methods approach (Pawson and Tilley, 1997), to acquire knowledge about how dance is impacting a group of people diagnosed with Parkinson's. There are strong debates in recent research about the use of a mixed methods approach and all that this term intends to suggest. In Denzin and Lincoln's 2011 handbook on qualitative research, John Creswell writes about the controversies and questions that surround this approach including its changing and expanding definitions, as well as the questionable use of qualitative and quantitative descriptors as they

seem to, “create a binary distinction that does not hold in practice,” (Creswell in Denzin and Lincoln, 2011). In discussing the latter point, Creswell makes a connection to work by Sandelowski et al. (2009) who point out that “counting often involves qualitative judgment and that numbers often related to context,” (Creswell in Denzin and Lincoln, 2011:272). In his chapter entitled “Controversies in Mixed Methods Research” Creswell discusses two definitions that encompass the ethos of this doctorate study:

“Mixed methods research is the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g., use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the purposes of breadth and depth of understanding and corroboration,” (Johnson et al., 2007:123).

“An orientation toward looking at the social world that actively invites us to participate in dialogue about multiple ways of seeing and hearing, multiple ways of making sense of the social world, and multiple standpoints on what is important and to be valued and cherished,” (Greene, 2007:20).

These two definitions discuss a mixed methods approach as being more than just the mixing of quantitative and qualitative means of data collection, but also as having an appreciation for quantitative and qualitative viewpoints that help guide the direction of the collection, analysis, and interpretation of data. The authors of

these definitions are demonstrating that there are multiple ways of seeing and making sense of the world or in the case of a particular research study, making sense of the results and findings. Correspondingly, this thesis aims to triangulate data from multiple different viewpoints or perspectives to gain further insight into the impact of dance on participants.

Martyn Hammersley writes about the multiple different meanings or interpretations of the word “triangulation,” (Hammersley, 2008). First he describes how triangulation can be meant to depict the gathering of data from different sources with different potential validity threats in an effort to reduce the chances of drawing inaccurate conclusions. He also talks of triangulation as a way to generate multiple, and sometimes differing interpretations of a particular situation. In this way, Hammersley talks of triangulation in a very similar way to Greene (2007) discussing the mixed methods approach and working with an understanding that there are multiple ways of making sense of the world. Thus, in this instance, triangulation of data is not being used to source out a single truth necessarily, but rather is being used to discuss how and why the data is bringing forth different information about the same situation. A third interpretation leads in to discussions of triangulation as a way of seeking complementary information so as to gain a richer and more complete picture of the phenomenon being studied (Hammersley, 2008).

Throughout the chapter Hammersley critically analyses how triangulation has been utilised in the past and the questions that need to be addressed. He argues that by combining different forms of data collection one is not necessarily

cancelling out the potential validity threats. Furthermore, he states it is important to remember that by combining data to seek further information about a particular situation, we still may not understand the full truth. The present thesis recognises Hammersley's critiques and aims to use triangulation in a way that does not assume we will understand the full truth about dance for people with Parkinson's after completing this work, nor will the potential limitations behind quantitative and qualitative methods be cancelled out simply by using both methods. The present thesis is using triangulation to understand better the relationships between the various ICF domains with the view that both measured change and perceived changes from the perspective of the participants are important in understanding this particular phenomenon.

It has been suggested that the choice of methodology should be determined through a critical understanding of the best way to answer the respective research questions, rather than a favouritism or "loyalty" to one paradigm or another (Krauss, 2005). Through embracing qualitative methods one may be better able to explain and form meaning around the numbers that result from quantitative assessments. Furthermore, by applying the same quantitative measures and questionnaires to all participants across all testing points, we may be able to describe the findings with more power thus providing stronger conclusions and answers to the research questions. In the context of dance for Parkinson's research, it appears that the measured changes and participant perception of those changes may be quite different and thus, understanding and reporting on only one perspective may be biasing our understanding of the impact dance is having on this population.

Considering the arguments made above it was determined that the best way to answer the research questions in the present thesis would be through a quasi-experimental research design with mixed qualitative and quantitative methods. This mixed methods approach is representative of more than just the inclusion of quantitative and qualitative data, but also blends methodological approaches and viewpoints. For example, while the present thesis will use quantitative methodologies to understand changes at various levels of the ICF framework, the study will also make use of qualitative research tools to investigate the participant experience and what they value about the ballet sessions. The chosen methods were born out of the view that it is important to understand how dance might impact this group of people from a variety of different perspectives, including the view of the participants as well as any potential changes that may occur at an unconscious level.

Jackson (2003) suggests that gaining knowledge through scientific methods involves both collecting data and testing hypotheses with this data. Conclusions are then made based on the logical and systematic analysis of such data. The present thesis will use experimental research methods to determine cause-and-effect relationships between variables of interest. However, qualitative methods such as observation and informal conversations as well as formal interviews were also carried out across the duration of the study to access more information about the participants and their experiences both inside and outside of the dance studio (LeCompte and Schensul, 2010). The mixed methods approach has allowed for a better understanding of how the ballet classes were impacting upon participants in all areas of their life.

3.2 Aims of the Study, Research Questions, and Hypothesis

Research Aims:

1. To employ a mixed methods approach to study the physical, mental, social, and emotional effects of dance on people with Parkinson's
2. To engage with and advocate for an internationally recognized framework that can be employed in future dance for Parkinson's research using findings from this mixed methods study
3. To better understand what dance can provide for people with Parkinson's that is similar or different to other physical activity forms
4. To determine relationships between variables being assessed to better understand the impact that dance can have on this population

Research Questions:

1. Does participation in a weekly ballet class help people with Parkinson's cope better with their motor and non-motor symptoms?
2. Does participation in a weekly ballet class help people with Parkinson's carry out activities of daily living with more ease and efficiency?
3. Does participation in a weekly ballet class for people with Parkinson's influence their levels of participation in the community and in society?
4. Does participation in dance offer additional benefits that may not be seen in other physical activity forms for people with Parkinson's?

Hypothesis:

Participation in a weekly ballet class will help people with Parkinson's to cope better with physical and mental symptoms, to carry out activities of daily living with more ease and efficiency, and will positively impact upon participation in society. As a result, participation in dance will have a positive impact on physical, psychological, emotional, and social health for this group of people and will therefore demonstrate additional benefits that may not be seen in other physical activity forms.

3.3 Context of Study

The present doctoral thesis is based on data collected for a larger project between University of Roehampton and English National Ballet (ENB). In 2010, ENB commissioned University of Roehampton to conduct research into the potential benefits of its weekly ballet-based dance sessions for people with Parkinson's. This pilot project was carried out over a 12-week time period and found positive results indicating that dance may provide significant physical and psychological benefit for people with Parkinson's. However, it was established that further investigation and a larger sample size would be needed to substantiate the conclusions drawn from this study and generalize the results to a wider population (Houston and McGill, 2013).

In 2011, ENB received funding to continue their weekly ballet classes for people with Parkinson's for an additional three years and University of Roehampton was

asked to conduct further research into the potential benefits for participants. Data collection for the second phase of the research commenced in spring 2012 and finished in summer 2014.

While the measurements used within the present thesis were used within the second phase of the wider project between University of Roehampton and ENB, the thesis has additional aims and objectives not necessarily addressed in the wider project. Along with wanting to better understand how dance can benefit those living with Parkinson's on multiple levels, this thesis aims to propose a new framework for Dance for Parkinson's research that encourages equal emphasis of physical, psychological, emotional, and social factors.

3.4 Basic Structure and Ethos of the Ballet Classes

The dance for Parkinson's work at ENB began as an artistic venture and as such, the aim of the researcher was not to control or influence the dance instruction in any way, but rather observe participants in an already existing dance project. As a result, I did not input on planning meetings to discuss choreography or exercises that participants should carry out with the aim of treating or relieving certain symptoms. Rather, the dance artists who led the ballet class used the current ENB company repertory as a basis for the content each term (see Appendix 2).

The choice to focus on the art form rather than specifically choosing exercises to treat or relieve certain symptoms is in keeping with recent aims brought forth by

the *Dance for PD*® programme, led by the Mark Morris Dance Company in New York (Westheimer, 2008). The inspiration for ENB's programme stems from the *Dance for PD*® model and the dance artists who led the ballet classes have worked closely with David Leventhal, Director of *Dance for PD*®. Through choosing to focus on artistic works and choreographies that the ballet company were performing at the time, the dance artists created an atmosphere that centred on the art form itself rather than using ballet as a therapeutic tool (McGill, Houston, and Lee, 2014). In this way, although participants may have been gaining a certain amount of therapeutic benefit from the classes, these benefits were not the primary focus of the sessions.

The once-weekly sessions in general followed the same structure across the duration of the study. All classes lasted between 1.25 and 1.5 hours during term time (autumn, spring, and summer terms each lasting between 10-12 weeks). The first half of the class began seated and then progressed to standing and to travelling movements. Seated exercises encouraged participants to move the spine through a full range of motion while also reaching the arms through a range of different ballet-based positions. Other exercises in the seated position focused on rhythmic work in the legs and feet. During these seated exercises participants were often asked to rotate and slowly twist in the spine. This action requires core abdominal muscles to engage while providing a dynamic stretch for muscles on the opposing side to the rotation. Some exercises asked participants to move their arms through a full range of motion at the shoulder joint and lift them as high as possible above the head. This movement can be quite challenging for those with stiffness in the thoracic region and a more stooped

posture. The rhythmic work in the legs and feet required participants to engage the hip flexors as they marched to the music while other exercises encouraged participants to extend the legs and lean forward providing a stretch for the hamstrings. Participants were asked to follow the instructors as they improvised with stamps and claps to the beat of the music.

The work then progressed to standing, often at the *ballet barre* where participants would carry out exercises focusing on knee bends and leg reaches. After these exercises participants would be encouraged to walk around the room. In this environment participants had to be spatially aware of their movement in relation to others in order to avoid collisions. They were also encouraged to quickly change directions and incorporate arm and hand gestures during their walk around the space. Near the end of class there was usually a small group dance where participants often worked with a partner. Movements in these small dance sequences included weight transfers, leg and arm reaches, and travelling steps. During the session, the musicians would lead one or two exercises with the focus on voice and rhythm. Although the programme uses the current company repertory as a basis for the content each term, the material is tailored to the participants' physical capabilities.

3.5 Research Design

As the ballet classes commenced prior to the start of the research project, this study did not work within a randomized design and the control participants were recruited specifically for the control group. Observation and participation in the ballet classes on a regular basis meant that the study was also not working within a blinded design for participants or researchers. A useful qualitative tool, participant observation allowed for close examination of the sessions as well as participant interaction and engagement. As such, participating in the ballet classes helped to engender trust amongst participants. Furthermore, by partaking in these sessions I was able to feel and experience the dancing alongside the participants. Through being immersed in the dancing experience, I was able to understand more about how dance was impacting this particular group of people and was also able to experience the bonded community that developed out of the dance classes. Therefore participation in the weekly classes helped to better answer the proposed research questions. During quantitative analysis, care was taken to treat all individuals, both dancing and control participants, the same to avoid influences of bias. For instance, the quantitative measurements were carried out in the same manner using the same protocol for both dancing and control participants. Furthermore, many of the measurements involved in the project, including biomechanical measures of gait as well as multiple participant questionnaires, do not necessarily allow for much subjective interpretation whereby data from control participants would be treated differently than data from dancing participants. Though there may be some subjectivity in the way the researcher handles data in general, or the way in which a particular participant

answers a question on a questionnaire, these are not examples of situations where all control participants are dealt with in a different way to all dancing participants. Thus, the consistency in protocols and measures across both groups would have helped to reduce bias.

The dance for Parkinson's classes at ENB are inclusive in nature and do not exclude participants from taking part due to disease severity. In keeping with the ethos of the classes, the research team involved in the larger project between ENB and University of Roehampton felt it was not appropriate to exclude participants from taking part in the research due to disease severity. Furthermore, the nature of the study led the research team to an ethical stance that it would not be appropriate to interfere with participants' medication plans. As a conscious choice was made to not interfere with medications, we were able to assess individuals at varying stages of their day. In this way the present thesis did not ignore the variability of the condition.

A number of studies in the field have asked participants to take medication prior to their testing session so that they were consistently tested in an "on" state. While this protocol is often put in place to ensure that the effects of the medications are not influencing the results, Parkinson's continues to be a highly variable condition even when people are on their medications. Therefore, even when participants are asked to take their medications directly before testing, results may still be influenced by the variability of the condition. Furthermore, there is question about how applicable the results from previous studies are when those participants are in a different state to when they were tested. The design of

the present study meant that researchers could account for the variability of the condition.

Full details of specific measurements and their protocols will be described in the relevant chapters. Briefly, the quantitative measurements consisted of a gait measurement with use of inertial sensors to assess step and stride variability as well as coordination and range of motion in the trunk, the Unified Parkinson's Disease Rating Scale (UPDRS), the Activities-Specific Balance Confidence (ABC) scale, and the Dance for Parkinson's questionnaire (DPQ) (see Appendix 3 for the DPQ). Qualitative assessments consisted of one-to-one, semi-structured interviews and focus group discussions as well as movement observations through attendance of the dance sessions and film footage.

The chosen quantitative and qualitative methods allowed for the assessment of variables that represent all domains of the ICF framework thus providing a deeper understanding of the impact dance might have on this group of people. While multiple studies in the field have incorporated measures of gait (Hackney and Earhart, 2010a; Duncan and Earhart, 2012; Marchant et al., 2010), no studies to date have looked at balance during walking as measured via step and stride variability. Furthermore, there is a lack of research looking specifically at coordination of the trunk during gait, even though recent studies have suggested that dance may help to improve coordination in people with Parkinson's (Heiberger et al., 2011).

A particularly important argument within the present thesis is that many studies in the field rely heavily on clinical rating scales to assess changes in balance. However, these scales do not distinguish between static and dynamic balance and the more commonly used scales focus heavily on static balance tasks alone. Given the risk of falls during locomotion for this group of people (Schaafsma et al., 2003; Hausdorff, 2009), this thesis argues for the need to vary methods of balance assessment and to include more dynamic measures of this variable. Gait variability measures have been closely related to fall rates in previous research (Maki, 1997; Hausdorff et al., 2001) and thus these measures were chosen for the present thesis (see Chapter Four for further information regarding step and stride variability). Though balance is often assessed in dance for Parkinson's studies, balance confidence is rarely assessed yet it plays a large role in what people with Parkinson's feel they can do in a standard environment. The ABC scale was chosen due to the ten-point rating scale that allowed the researcher to detect smaller changes in this variable. Furthermore, the questions in this scale closely reflected functional everyday activities, helping to understand changes in the second domain of the ICF (Powell and Myers, 1995).

Cross correlation has been used previously to assess the coordination between two parts of the body in motion (Shum et al., 2007; Lee and Wong, 2002). People with Parkinson's tend to move the pelvis and thorax in a more in-phase pattern during walking due to rigidity in the trunk (Murray et al., 1978), but no studies in the dance for Parkinson's field have addressed whether dance can help to improve trunk coordination specifically (see Chapter Five for further information regarding cross correlation of trunk movements).

The UPDRS has been used in many other studies in the field and is used in clinical settings to assess stage of condition (Goetz et al., 2007; Heiberger et al., 2011; Marchant et al., 2010; Hackney and Earhart, 2009a). While the inclusion of the scale allowed for comparison to previous research findings, it also allowed for the assessment of multiple ICF domains within one scale (non-motor impairments, motor impairments, and activities of daily living) (see Chapter Six for further information regarding the UPDRS).

The Dance for Parkinson's questionnaire (DPQ) was chosen to assess a range of quality of life factors that might influence one's level of participation in society (the third domain of the ICF). Studies have shown a direct link between participation restrictions and reduced health-related quality of life (Duncan and Earhart, 2011; Sabari et al., 2015). This particular scale was recently devised specifically for dance for Parkinson's studies and is composed of relevant subscales from a variety of previously validated questionnaires (McRae et al., 2004). Again, the scale allowed for the assessment of variables representative of multiple ICF domains from the participants' point of view (see Chapter Seven for further information regarding the DPQ). By gaining the participants' perception of their impairment, difficulties with everyday tasks and other quality of life factors, this study allowed for further discussion about the correlation between changes in participant perceptions of their condition and measured changes in other assessments.

Semi-structured interviews and focus group discussions were essential in helping to answer the research questions and gain an understanding of how dance was

affecting the participants physically, mentally, emotionally, and socially. Within the focus group discussions a theme was normally taken or one question used to prompt discussion amongst participants. It was only by talking with participants that the value of the ballet classes for this group of people could be fully understood (see Chapters Seven and Eight for further information regarding the use of interviews, focus group discussions, and informal conversations for this PhD study).

Although not discussed in the analysis for this PhD thesis, the data collection also included a posture measurement utilising an electromagnetic tracking device to assess spinal angles (Singh et al., 2010). As mentioned previously, a stooped posture is a cardinal symptom of Parkinson's causing much discomfort and pain and may also lead to reduced stability and falls. The posture measurement was included in an effort to better understand how dance may be impacting this particular symptom. Unfortunately the accuracy of this data could not be confirmed with many participants finding it difficult to stand still for longer periods of time due to pain and severe dyskinesia interfering with the results. Thus, the data from this particular measurement has been removed from the thesis and will not be discussed further.

This study collected data at the beginning of autumn term (September 2012) and then subsequently after each dancing term until July 2014. This approach allowed for the maximum amount of data to be collected for participants across the duration of the study, including those participants who joined at a later date.

Details of how this information was analysed will be discussed later in section 3.9.

3.6 Participant Recruitment

Inclusion criteria set at the beginning of the study meant that all participants, both dancing and control groups, had to be over 55 years of age, show no signs of dementia, be able to walk, or attempt to walk independently with no walking aid, and have no back injury or have had recent surgery on the back. Additionally for biomechanical measurements of gait with use of inertial sensors the participants must not have gone through Deep Brain Stimulation surgery. All dance participants had been dancing prior to baseline measurement for at least one term (or three months). The majority of participants had been taking part in dance classes for one year or more prior to their baseline measurement.

A research briefing paper (see Appendix 4) and a small presentation were given to all members of the dance class to outline the various measurements and explain what would be asked of them if they chose to take part. Once enrolled, they were provided with a detailed consent form (see Appendix 5). While many of the dancing participants joined the research at the onset of the study, there were some participants that joined at a later date. All dancing participants had joined the project by July 2013. A total of 27 dancing participants took part in these measures throughout the duration of the study but 3 were removed from the final analysis (1 participant moved abroad, 1 participant did not feel well enough

to continue attending, and 1 participant was not able to attend enough testing sessions).

Control participants volunteered to take part in the research testing sessions but agreed to not take part in any dance classes. Although this may have presented some ethical concerns (see section 3.8 of this chapter), many of the control participants noted that they would not have been interested to take part in dance classes in any case. To recruit participants I attended multiple Parkinson's support group meetings to talk about the research with control participants and briefing papers were distributed (see Appendix 6). Parkinson's UK also sent details about the present study to individuals on their mailing list and members of the dancing group were asked if they could advertise the research in their local Parkinson's UK support group meetings. Participants were offered reimbursement for their travel expenses to and from the testing sessions. Once enrolled, they were provided with a detailed consent form (see Appendix 7). Across the duration of the study, a total of 15 people were recruited for the control group, with the final control participant recruited in October 2013.

3.7 Participant Health Information

Participants in both the dancing and control groups were often dealing with a variety of other medical conditions alongside their Parkinson's. At each data collection participants were asked to complete a health information sheet (see Appendix 8). Whilst some conditions dissipated after a few weeks, other

conditions would have certainly impacted on the participants' health and wellbeing in this study.

Across the duration of the study one participant was diagnosed with cancer and underwent chemotherapy treatment, one participant suffered a stroke, multiple participants suffered from extreme pain in the back and legs, and others suffered from bladder and urinary infections as well as bowel issues. A couple of participants had been diagnosed with arthritis and one participant was waiting upon a formal diagnosis for Sciatica. Another participant was diagnosed with Polymyohgia Ruematica and Angina and others experienced a wide range of common colds, chest infections, and flu across the two years of the research study. One of the dancing participants underwent deep brain stimulation (DBS) surgery during the study while three other dancing participants had already completed this surgery prior to volunteering for the project. One control participant had also undergone this surgery prior to volunteering for the project. There were no other neurological conditions reported by the participants.

All participants were taking medication for their Parkinson's by the end of the study with most participants taking a form of Levadopa. One participant in the dancing group began the project not taking any Parkinson's medication but midway through began taking Levadopa-based treatment. Many participants were also taking additional medications for a variety of other conditions as well as to help relieve side effects from their current Parkinson's medications.

Almost all participants, in both dancing and control groups, were involved in other physical activities on a weekly or monthly basis. Some examples of activities carried out by participants include golfing, swimming, Pilates, yoga, Tai Chi, Physiotherapy, attending the gym, racket ball, rowing, and exercise/aerobic-based classes. Furthermore, when asked about other physical activities that they take part in on a regular basis, many participants made note that active homemaking, gardening, and cleaning presented a good amount of daily physical activity.

Please see Tables 7.1-7.3 located in Appendix 9 for information regarding participant physical activity levels and reported falls as well as percentage of ballet classes attended for each dancing participant.

While this study aimed to assess fall rates using the health and information form, it was evident during analysis that participants interpreted the definition of a fall in very different ways. This caused problems in the analysis of the data and it would not have been appropriate to calculate means and standard deviations using the numbers provided. As such, this information has been included in the appendices and will be discussed further when looking at specific case studies in Chapter Eight.

While the majority of participants attended over 50% of the ballet classes provided across the time that they were analysed for the study, there were some exceptions to this finding. Attendance as a contextual factor will be discussed in further detail in Chapter Eight of this thesis.

3.8 Ethical Considerations

Participation in the research was voluntary and ethical clearance was gained from the University of Roehampton Ethics Committee. It was made clear at the onset of the study that participation was voluntary and that individuals could withdraw from the research at any time without prejudice. Furthermore, it was made clear that participants could avoid a particular component or test and still remain within the research project.

Paper data was kept in a secure place and electronic data was stored on a password-protected computer and two external hard drives. Data gathered from biomechanical measurements, clinical rating scales, and questionnaires were kept anonymous by putting an ID number in place of the participants' name. A document was kept in a separate file on a personal computer and hard drive that listed the names and numbers for all participants. However, there was a need to have access to names in order to triangulate data across all data collection methods, several of which could not be made anonymous at the point of data collection (such as the interviews, or observation of individuals within the class setting).

ENB was wholly responsible for the delivery of the sessions and adhered to its own internal procedures for gaining consent from participants to take part. This consent included checking with a doctor before joining in, whether or not they consent to their photograph being taken or being filmed by ENB, the research team or outside film companies for publicity or educational purposes, listing

another contact in case of emergencies, and signed understanding that they take part at their own risk. Taking part in the research was a separate decision to whether participants took part in the dance classes.

An initial ethical concern that was considered by the wider research team was the idea that the assessments used might draw attention to the person's disease and the progression of their condition. As such, the researchers were careful to respond sensitively to participants' moods and worked hard to avoid highlighting this issue. For instance, all of those involved in data collection or helping on the day of testing were encouraged to engage in conversation with participants and help them to feel comfortable and at ease. Conversations often drifted away from their Parkinson's symptoms and on to other topics such as family events in the nearby future or their recent visits to the theatre.

Prior to the onset of data collection, there was an awareness that there may be a number of people with Parkinson's in the space during the testing sessions and that they may need extra care or help. As such, it was of upmost importance that volunteer student helpers were recruited to help create an easy and pleasant experience. Prior to each testing session, I contacted Bachelor of Arts (BA) dance students from University of Roehampton via email and in person to ask for volunteers. Those who volunteered were then sent a volunteer briefing paper (see Appendix 10) that provided a brief explanation of Parkinson's and symptoms that individuals commonly experience, as well as an outline of the measurements and what would be asked of them. Student volunteers were either placed on station one that focused on biomechanical measurements, station two that

focused on clinical rating scales, or station three where volunteers were responsible for welcoming participants and reviewing paperwork. The paperwork consisted of the health and information sheet as well as the UPDRS participant questionnaire, the ABC scale and the DPQ that were to be filled out prior to arriving at the testing sessions.

Knowing that one is in a control group, rather than a participant in a project that may positively benefit symptoms of Parkinson's, may generate feelings that one has 'missed out', or that one would like to try dancing. Although most of the control participants did not show interest throughout the study to get more involved with dance for Parkinson's classes, participants were offered help in locating a class after completing the study if they wished to get more involved. Control participants were also encouraged to carry on with their normal activities.

3.9 Overview of Analysis

After each testing session data was inputted into a separate excel sheet and kept in a results folder. All data gathered from biomechanical gait measurements went through formal analysis methods in Matlab (Mathworks, 2015) and final values were inputted into the relevant results sheet. All interview audio recordings were transcribed and saved in the results folder (see Appendix 11) along with transcribed hand written notes from the interviews, focus group discussions, and informal conversations with participants. Specific analysis methods for the quantitative and qualitative data will be discussed in forthcoming chapters.

Upon completion of the final data collection, overall means and standard deviations (SDs) were calculated from the raw data. This first step of the analysis helped draw attention to the non-normal distribution of the quantitative data. Furthermore, across the seven testing sessions, most participants had missed at least one or two testing sessions. There were a variety of reasons for why participants may not have been able to attend a particular session including not feeling well enough to attend, weather conditions with respect to travelling to the studio, or other important events such as a family gathering. As such, there were varying sample sizes across the seven testing sessions with the composition of the group also changing depending on who could attend and when.

In order to help manage issues of missed data from non-attendance at the data collection points, an analysis map was created to outline which data collections participants had attended across the duration of the study (see Table 7.4 in Appendix 12). Upon reviewing this information it was decided that it would be possible to examine each participant using a short-term and long-term analysis. Due to some participants having to miss certain testing sessions as well as the fact that some participants joined the study later while others had to leave early, the short term and long term analysis happened at different points throughout the study for different individuals. However, the short-term analysis always looked at one term of dancing and the long-term analysis always looked at three terms of dancing. While each term varied slightly with respect to number of dancing weeks and choreography used, raw data demonstrated no large changes in variables across all terms. Thus, it was determined that this analysis method

would be appropriate to use and would allow for the inclusion of participants who joined at different points throughout the study.

Once the analysis map had been finalized, an SPSS data file was created and all relevant quantitative data was inputted. For each participant, there were three testing points included in the SPSS file (baseline, short term, and long term). After data input was complete, the SPSS file was crosschecked with all submitted paper work and any errors or missing data were logged. Any logged errors were then crosschecked again with notes from that particular testing session to make sure that the error was not an intentional change of value.

When a participant did not complete a particular measurement, a value of 999 was placed in the SPSS data file and the statistical measures calculated the outputs accordingly. With regards to the UPDRS, the ABC scale, and the DPQ, situations arose where participants had completed the majority of the subsections and scales but had missed one or two questions. In this case, the total score for that subsection was divided by the number of questions completed, and then multiplied by the total amount of questions in the scale. This method of accounting for missing data was only used when participants were missing less than 25% of the questions in that particular scale. If participants were missing more than a quarter of the questions, a total value of 999 was inputted into the SPSS data file to represent missing data.

3.10 Reporting the Results

The following five chapters will report on the findings from this PhD study. Chapters Four and Five focus on changes in gait variables and thus are more representative of the first domain of the ICF framework. Chapter Six looks at changes in motor aspects of everyday activities in relation to non-motor and motor impairments and is representative of the second domain of the ICF framework. Chapter Seven focuses on changes in aspects of quality of life that may influence participation in society and thus is representative of changes within the third domain of the ICF framework. As discussed in section 2.8.1, the ICF also takes into consideration personal and environmental contextual factors that may impact upon the three aforementioned domains. Chapter Eight is composed of five case studies that enable the domains of the ICF framework to be discussed in relation to one another while also taking into consideration any contextual factors that may impact upon impairment, activities of daily living, and participation in society for the individual. Chapter Nine will discuss in more detail some of the key findings from the project and will provide recommendations for future research in the field.

Chapters Four, Five, and Six have been submitted as journal articles for publication and are currently under review.

Chapter Four

Effects of a ballet-based dance intervention on gait variability and balance confidence of people with Parkinson's

4.1 Introduction

Individuals with Parkinson's are at a much higher risk of falling compared to age-matched controls and these falls can lead to a multitude of injuries, a fear of falling, decreased balance confidence, and a subsequent lack of participation in activities and in society (Schaafsma et al., 2003; Hausdorff, 2009). As a result, balance problems can have a detrimental impact on an individual's health-related quality of life and may be the source of low self-esteem and social isolation in many cases (Bloem et al., 2001).

Recent studies examining the effects of physical activity for this population have attempted to understand how balance can be improved (Schenkman et al., 2012; Ashburn et al., 2007). Balance specifically has been a main concern for researchers in the dance for Parkinson's field. To date, studies have only postulated about how dance, in a variety of forms, may be affecting balance (Earhart, 2009). No studies have directly measured the mechanisms of change or exactly how specific dance movements are influencing stability within this group of people. Instead, recent studies have only suggested that the practice of weight shift, quick changes of direction, and the teaching of movement strategies may be cause for the improved balance and gait after a dance intervention (Hackney et al., 2007; Earhart, 2009).

There is reason to suggest that ballet exercises would have a positive impact on gait and balance confidence for this group of people. A variety of movements in a ballet class require the participant to stabilize on one leg while moving the

other leg through a range of motion, as is seen in a *tendu* or *rond de jambe* action. Furthermore, travelling sequences across the floor encourage efficient transfer of weight and an understanding of how to bring the centre of mass over the base of support to re-stabilize while in motion. Thus, it is important to understand more about how ballet could potentially benefit people with Parkinson's, and specifically their stability.

As discussed in Chapter Two, many studies have relied on clinical rating scales to assess functional changes in stability after a dance intervention. However, recent research has expressed concern that these scales might be assessing efficiency of completing specific tasks rather than changes to balance overall (Houston and McGill, 2013). Furthermore, these rating scales do not distinguish between stability in standing (static) and stability in motion (dynamic), with some of the most common measures in the field only assessing static balance. There is a need to better understand the significance of stability during common functional activities such as walking.

Hausdorff (2009) makes note of the large impact that a disturbed gait pattern has on the high risk of falls evident in this population. Gait variables that are often associated with Parkinson's include a reduced gait speed, shorter stride length, stooped posture, and reduced arm swing. Additionally gait instability and arrhythmicity, resulting in higher stride-to-stride variability, are characteristic features of Parkinsonian gait (Schaafsma et al., 2003). Several research papers have noted that the measurement of gait variability specifically relates more to fall risk than the measurement of other cardinal symptoms such as tremor,

rigidity, and bradykinesia (Schaafsma et al., 2003; Hausdorff, 2009). In other clinical populations, gait variability is more closely related to fall rates than other gait variables such as average step length or walking speed (Maki, 1997; Hausdorff et al., 2001).

Analysis of acceleration signals reflecting movements of the centre of mass has proven to be useful in the measurement of dynamic stability (Moe-Nilssen, 1998). Numerous studies have assessed the temporal variability of gait patterns through autocorrelation of acceleration signals (Yang and Hsu, 2010; Yang et al., 2011; Keenan and Wilhelm, 2005). Autocorrelation is the correlation of a signal with itself at different time lags. At zero lags two identical signals will produce a coefficient of one. At a particular phase shift the autocorrelation coefficient will be at its maximum again evidencing how similar the two signals are when the time lag is representative of one step. A coefficient value closer to one is representative of a stronger similarity between neighbouring steps. The coefficient values can thus provide an indication of the step and stride regularity, or variability, for a particular gait pattern and are a useful tool for measuring dynamic stability (Yang et al., 2011; Moe-Nilssen and Helbostad, 2004).

McGill, Houston, and Lee (2014) argue that it is important to understand how changes to physical impairments are impacting upon participants' daily lives and activities. With regards to balance and changes to dynamic stability, it is important to understand how the participants feel about their ability to remain stable and safe in everyday tasks and situations. However, few studies to date have included measures of balance confidence.

Marchant et al. (2010) looked at changes in balance and confidence after a short duration, high dose contact improvisation intervention for people with Parkinson's. While the study found significant improvements in balance as measured by the Berg Balance Scale, results from Activities Specific Balance Confidence Scale (ABC) were not discussed (Marchant et al., 2010). Thus, the findings in this study are unclear with regards to changes in balance confidence. The ABC is a 16-item scale asking participants to rate how confident they feel at attempting various tasks that require some level of stability. The scale provides an indication of participants' balance confidence in activities of daily living (Powell and Myers, 1995; Parry et al., 2001). Myers et al. (1998) suggest that an ABC total score between 50% and 80% is reflective of a moderate level of physical functioning whereas a score below 50% is indicative of a low level of physical functioning. Furthermore, Lajoie and Gallagher (2004) suggest that an ABC score below 67% may indicate a higher risk of falls for older adults and is a predictor of future falls.

This chapter aims to determine if weekly ballet classes can affect dynamic stability as measured by gait variability for a group of people with Parkinson's. The chapter also aims to understand if participation in weekly ballet classes impacts upon balance confidence for this group of people.

4.2 Methods

4.2.1 Participants

A total of 19 people diagnosed with Parkinson's who were dancing once a week with ENB were analysed for the purposes of these measures. A total of 13 control participants who were not involved in any dance classes formed the control group.

Table 1.1 Participant characteristics

	Age	Gender	Years Diagnosed	Stage of Parkinson's	UPDRS Motor Subscale Score	MMSE score
Experimental Group	69.42 ± 4.55	10/9 (F/M)	6.47 ± 2.95	2.32 ± 0.48	29.42 ± 9.11	28.37 ± 1.57
Control Group	73.25 ± 8.09	7/6 (F/M)	5.92 ± 4.13	2.15 ± 0.55	31.69 ± 10.31	28.23 ± 1.64

4.2.2 Step and Stride Variability Assessment

To assess step and stride variability a single inertial sensor was placed at the sacrum of the participant (S2) and secured with double-sided tape. The inertial sensor wirelessly sent information to a receiving box attached to a computer. Linear acceleration data were gathered at a rate of 180Hz (Moe-Nilssen and Helbostad, 2004; Brach et al., 2011; Esser et al., 2011). Moe- Nilssen (1998) discusses the validity of choosing the sacrum as a reference point which is close to and moves in parallel with the centre of mass of the person. The present study chose a position on the sacrum (S2), as this particular sensor would also be used for further measurements of pelvic range of motion during walking. Changes to pelvic range of motion will be discussed in a separate chapter.

Participants were asked to walk from one side of the room to the other (a distance of 10m) at a self-selected, natural walking speed. Data was only recorded in one direction to avoid acceleration signals switching from positive to negative values and thus participants stopped after the 10m walk, data was saved, and the researcher and participant walked back to the same starting point to complete the rest of the trials. Each participant carried out three trials in total at each testing point.

4.2.3 Balance Confidence Assessment

Balance confidence was assessed using the Activities-Specific Balance Confidence Scale (Powell and Myers, 1995). Participants were asked to complete the questionnaire prior to attending their testing session. If they had any queries or concerns about any of the 16 questions, they were asked to make note of these issues and raise them with the researcher at their testing session.

4.2.4 Data Analysis

Gait and balance confidence data were analysed across the short term (3-5 months) and across a longer term (10-12 months). For each separate gait trial, five stride cycles were analysed from the middle of the data set with the first and last cycles avoided where possible to remove any data reflecting the start up or slowing down at the end of the walk. The five cycles were determined by using the vertical acceleration signals to locate heel strikes (Evans et al., 1991). A

single stride was represented by the heel strike of one foot and the time to the next point of contact where that same heel contacted the floor.

Prior to determining the 5 cycles for analysis, the vertical acceleration data was resampled using the Butterworth filter in Matlab. This allowed for a smoothing of the data. Unbiased autocorrelation methods were used in Matlab with the <xcov> function serving to compute autocorrelation coefficients representative of step and stride variability.

With regards to balance confidence, scores for each of the 16 questions were totalled and divided by 16 to provide an average score.

4.2.5 Statistical Analysis

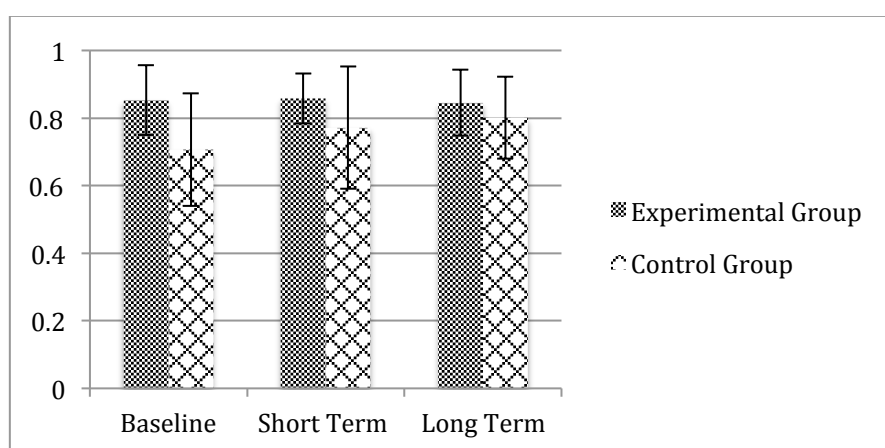
Normality tests (the Kolmogorov-Smirnov (K-S) test and Shapiro-Wilk test) showed that the data sets did not have normal distributions and thus it would not be appropriate to use parametric statistical tests. For all variables, the Friedman test was used to calculate changes across time in the dancing group and in the control group. Mann Whitney U tests were used to calculate differences between groups at each of the three time points (baseline, short term, and long term). A Spearman Rank Correlation was used to assess the relationship between gait variability and balance confidence in the short and long term. All statistical tests were carried out in SPSS with a significance level set at $p < 0.01$.

4.3 Results

4.3.1 Step Variability

Figure 2.1 outlines changes to step variability across time for both dancing and control groups. While the dancing group fell slightly towards a more variable step pattern, the control group grew towards a more consistent step pattern. The dancing and control groups did not evidence any significant change across the duration of the study with respect to step variability ($p=0.635$ and $p=0.15$ respectively). There were also no significant differences between groups with respect to step variability (baseline ($p=0.013$), short term ($p=0.317$), long term ($p=0.295$)). However, it appears that the two groups grew to be more similar across the duration of the study. Additionally, the dancing participants always demonstrated a more consistent step pattern compared to control participants.

Figure 2.1 Changes in Step Variability

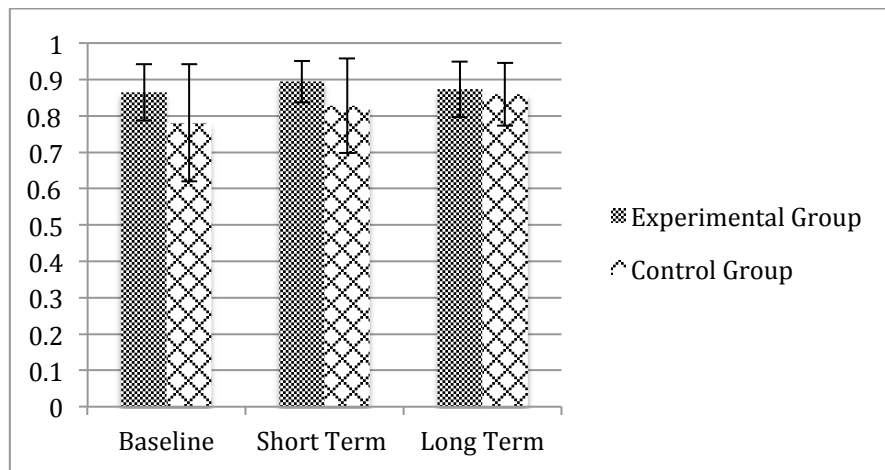


*Error bars represent standard deviation values

4.3.2 Stride Variability

Figure 2.2 outlines changes to stride variability across time for both dancing and control groups. Both groups saw a slight move towards a more consistent stride pattern by the end of the study. However these changes were not significant ($p=0.199$ and $p=0.614$ respectively). There were also no significant differences between groups with respect to stride variability (baseline ($p=0.235$), short term ($p=0.299$), long term ($p=0.365$)). Again, the two groups grew to be more similar across the duration of the study with the dancing participants always demonstrating a more consistent stride pattern compared to control participants.

Figure 2.2 Changes in Stride Variability



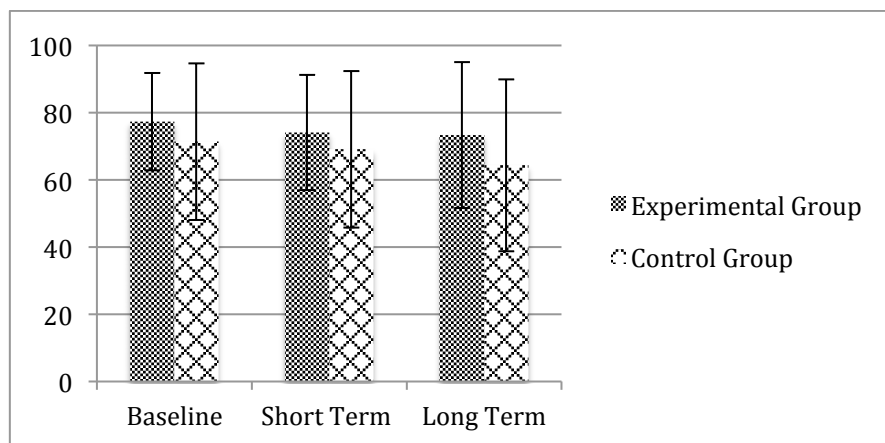
*Error bars represent standard deviation values

4.3.3 Balance Confidence

Figure 2.3 outlines changes to balance confidence across time for both groups. The dancing and control groups did not see any significant change in balance

confidence across time ($p=0.754$ and $p=0.087$ respectively). Furthermore, there were no significant differences between groups across the duration of the study (baseline ($p=0.759$), short term ($p=0.626$), long term ($p=0.350$)). Both the dancing and control groups remained within the 50 to 80% range throughout the duration of the study evidencing a moderate level of functioning (Myers et al., 1998). Across the study the control group fell below 67% thus putting them at a higher fall risk, whereas the dancing group began the study above a 67% confidence level and remained above this value throughout (Lajoie and Gallagher, 2004).

Figure 2.3 Changes in Balance Confidence



*Error bars represent standard deviation values

The table below outlines the means and standard deviations for all variables across time for both dancing and control groups.

Table 1.2 Changes in Step Variability, Stride Variability, and Balance Confidence

	Dancing Group			Control Group		
	Baseline	Short Term	Long Term	Baseline	Short Term	Long Term
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Step Variability	0.853 (0.103)	0.859 (0.074)	0.845 (0.098)	0.707 (0.167)	0.772 (0.181)	0.801 (0.121)
Stride Variability	0.864 (0.077)	0.894 (0.057)	0.873 (0.076)	0.781 (0.161)	0.828 (0.130)	0.859 (0.086)
Balance Confidence	77.33 (14.54)	74.05 (17.14)	73.28 (21.74)	71.38 (23.30)	69.13 (23.31)	64.38 (25.61)

4.3.4 Correlation between Step/Stride Variability and Balance Confidence

Short term

While there was a significant positive correlation between step and stride variability ($r=0.796$, $p=0.000$), there were no significant correlations between step variability and balance confidence ($r=-0.331$, $p=0.106$) or between stride variability and balance confidence ($r=-0.151$, $p=0.471$).

Long Term

While there was a significant positive correlation between step and stride variability ($r=0.700$, $p=0.000$), there were no significant correlations between step variability and balance confidence ($r=-0.354$, $p=0.106$) or between stride variability and balance confidence ($r=-0.345$, $p=0.116$).

4.4 Discussion

Our results are different to those of many other dance for Parkinson's studies that have assessed changes in balance. While numerous studies in the field have shown positive improvements to balance after a dance intervention (Hackney and

Earhart, 2010a; Hackney et al., 2007; Batson, 2010; Marchant et al., 2010), the results from the present study show no significant changes in gait variability after 12-months of participation in a weekly ballet class. The reasons for this difference in result are two-fold. First, dynamic stability during walking as measured through gait variability has not been assessed in previous dance for Parkinson's research. Measures of gait variability are not necessarily comparable to other commonly used clinical rating scales that place more emphasis on static balance tasks (Moe-Nilssen, 1998). As gait variability is closely related to fall rates (Schaafsma, 2003; Hausdorff, 2009; Maki, 1997), the present study is providing new, useful information in demonstrating that weekly ballet classes did not have a significant effect on gait variability and potentially the risk of fall. Secondly, previous studies evidencing changes to balance, gait, and functional mobility have often included a class frequency of two to three dance classes per week (Hackney and Earhart, 2009a; 2010a; Hackney et al., 2007). It is possible that a frequency of one dance class per week will not elicit positive physical improvement for this group of people (Shanahan et al., 2015). The present study found no significant effects on gait variability with a frequency of one ballet class per week. It is unclear what the effect will be with a different frequency and thus further investigation is needed with regards to ballet for people with Parkinson's specifically before we can comment on ballet in comparison to other dance forms.

This is one of few studies to look at a group of people with Parkinson's who had already been dancing prior to baseline measurement. As many participants had already been dancing for at least one year prior to baseline, the results may

reflect the physical plateau that happens when there is a lack of overload on the body system. The principle of overload in exercise and conditioning research reinforces the need for consistent, incremental rises in training factors such as frequency, intensity, duration, and type of training (Shanahan et al., 2015; Power and Clifford, 2013). With regards to the dance classes in the present study, the frequency and duration remained the same with some level of change in the intensity and type of dancing as a result of changes to choreography from term to term. However, these changes in intensity during the weekly sessions were not large enough to warrant significant changes in stability.

In certain contexts within motor control analysis, variability and increased degrees of freedom are often viewed as being a positive factor, allowing the individual to respond appropriately to a wide variety of potential environmental changes (Rosenblatt et al., 2014). Literature in human movement analysis suggests that it would not be appropriate to conclude that all variability is either problematic or beneficial. “Rather, it is more plausible to propose that variability may be classified in either category depending on its observed effect on the movement or task of interest,” (Hamill et al., 2006:160). Studies that have focused on variability in stride duration have shown that variability is a strong indicator of those with a history of falls and those with degenerative conditions such as Parkinson’s and Huntington’s disease (Hausdorff et al., 1998). However, Dingwell et al. (2001) showed that stride-to-stride variability as assessed using Lyapunov exponents is a poor indicator of dynamic trunk stability. Research by Hamill et al. (1999) suggested that low variability in joint-segment coupling within the knee was representative of injury while higher variability in healthy

controls allowed for “multiple combinations of coupling actions that would not repeatedly stress the soft tissue,” (Hamill et al., 2006:161). However, their results did not confirm that the low variability was a direct cause of the knee injury.

Work by Gabell and Nayak (1984) suggests that a certain amount of step width variability may be beneficial in maintaining stability however if this variability is too low or too high it may indicate an inability to adapt to perturbations or a changing environment. This idea raises questions about whether there is an appropriate bandwidth of variability that gait patterns should aim to achieve. The uncontrolled manifold hypothesis (Sholz and Schoner, 1999) proposes that when performing a specific task, the involved components such as joint and muscle action are restricted to a range that will allow for successful completion of the task. While variability will exist within that range, the task will still be completed successfully provided the components stay within the restricted range of action.

The present study did not choose to look at step width variability, variability in stride time, or muscle and joint actions during gait. Instead the study looked at variability in the vertical acceleration patterns of the centre of mass (COM) during normal walking. Vertical acceleration was chosen specifically due to the clarity in detecting subsequent heel strikes from the data thus providing a clear understanding of the COM movement between each step and each stride. Participants were asked to walk from one end of the room to the other in a straight path on a flat surface with no obstructions or constraints. In these conditions participants were not dealing with perturbations caused by external factors in the environment but only the perturbations caused by any issues with

internal balance systems (i.e. the vestibular and proprioceptive systems for example). When walking in such conditions research has shown that healthy gait patterns demonstrate a more consistent rhythm as there is no need to adapt to external perturbations or changes in the environment in such a controlled setting (Hausdorff, 2005; Terrier and Schutz, 2003).

Latt et al. (2009) studied the temporospatial gait parameters and acceleration patterns of the head and trunk in older people with and without Parkinson's. The researchers looked at comparing those with and without Parkinson's but also those with Parkinson's who did and did not have a history falls. Results showed that those with Parkinson's demonstrated significantly less rhythmic acceleration patterns at the head and pelvis in all three planes. Furthermore people with Parkinson's who had a history of falls demonstrated significantly less rhythmic accelerations at the pelvis in the vertical and anteroposterior planes than non-fallers. These authors state that their findings are consistent with previous research in suggesting that vertical and anteroposterior measures of upper body movement are more closely related to gait stability than measures in the mediolateral plane.

While a certain amount of variability may be beneficial with regards to other gait variables such as step width, research suggests that the lack of rhythmic movement in the trunk is indicative of those with impaired stability (Latt et al., 2009; Menz et al., 2003; Keenen and Wilhelm, 2005). Thus, gait variability can be a good indicator of changes in dynamic stability and may provide new insights into the effects of dance-based activity on balance for people with

Parkinson's.

Previous research has emphasized the strength of analysing a particular situation or variable from multiple different perspectives (Houston and McGill, 2013; McGill, Houston, and Lee, 2014). Chapter Two argued for the need to understand how potential physical changes impact upon activities of daily living and participation in society. The chapter suggested that making these connections would help to develop more meaningful conclusions about the impact dance is having on people with Parkinson's.

The present chapter followed on from the argument above and included an additional measurement looking at participant perceptions of balance confidence with regards to activities outside of the dance studio. Across the duration of the study there were no significant changes to balance confidence for the dancing and control groups. Since there were no such significant changes, it would be difficult to interpret any correlation between gait variability and confidence. However, the present study did not find any significant correlation between these two variables in any case.

Finally, it should be pointed out that although the present study did not see any significant changes to dynamic stability or balance confidence, the ballet classes may provide other social, emotional, and psychological benefit that would impact upon daily activities and participation. These additional benefits will be discussed in chapters seven and eight.

4.5 Chapter Summary

The results demonstrate no significant changes in step and stride variability or balance confidence after 12 months of weekly ballet classes for a group of people with Parkinson's.

Future research should continue to assess potential changes in dynamic stability and the impact upon daily activities as a result of participation in different protocols of ballet-based classes. For instance, assessing these changes in an intervention protocol with increased frequencies of classes per week would help researchers identify optimal training frequency. Furthermore, applying the principle of overload may help to avoid physical plateau over a longer period of time. Future research also needs to look at the mechanisms of change with regards to ballet for people with Parkinson's. Through understanding the effects of specific movements and how frequently participants need to practice those movements, we may be better able to make clearer recommendations about dance for people with Parkinson's. Future research in the field should also look at the psychosocial effects of dance interventions and substantiate the conclusions we are making about dance having a significant positive impact upon people with Parkinson's.

Chapter Five

Effects of a ballet intervention on trunk coordination and range of motion during gait in people with Parkinson's

5.1 Introduction

Recent studies have evidenced the effect of instability and dysfunctional gait patterns on fall risk for people living with Parkinson's (Hausdorff, 2009). Characteristic features of Parkinsonian gait include a smaller step and stride length, increased double support time, increased cadence, decreased walking velocity, and instability with greater step and stride variability. Individuals tend to walk with a flexed posture and demonstrate a reduced or absent arm swing with rigidity in trunk movements (Hackney et al., 2007; Van Emmerick et al., 1999; Morris et al., 1994; Pedersen et al., 1997). Along with the fact that people with Parkinson's often find they have decreased clearance of the swinging leg from the floor, this can put them at risk of falling during dynamic situations (Hausdorff, 2009; Hackney et al., 2007).

The array of difficulties that people may face with their gait can have a detrimental impact on functional mobility and thus participation in everyday activities. Heiberger et al. (2011) suggest that dance as a physical activity comprises elements that may help to improve rhythmic motor coordination and balance. However there is insufficient evidence to support this argument as studies in the field have not gone so far as to measure exactly which elements of a dance class elicit change in these variables.

In the first study that looked at ballet for people with Parkinson's, Houston and McGill (2013) qualitatively observed that weekly sessions helped to improve fluency of movement. Actions that encouraged isolation of the upper from the

lower body appeared to improve trunk rotation. However, this study did not have any control group, and was only of very short duration (Houston and McGill, 2013).

Previous studies that focused on the benefits of dance for this population often included gait parameters in their methods (Hackney and Earhart, 2010a; Duncan and Earhart, 2012; Marchant et al., 2010). Common gait measures include the 6-minute walk test (6MWT), the Timed Up and Go test (TUG), and biomechanical measures that assess walking velocity. However, these measures only assess how quickly a participant can cover a certain distance over a period of time. The quality of walking and other gait parameters are equally important. More recent studies have attempted to address this issue by including such variables as step and stride length and time spent in stance and swing phase (Marchant et al., 2010).

However, there is still a lack of research that looks at changes to trunk coordination as a result of participation in dance. This is particularly important in people with Parkinson's who have shown to exhibit trunk rigidity (Huang et al., 2010). In healthy gait patterns the pelvis moves into a forward rotation on the side of the swinging leg and an opposite rotation happens near the end of the stance phase. This pelvic motion must be counterbalanced, either by counter-rotating the thorax or by swinging an arm (Crosbie et al., 1997; Stokes et al., 1989). Stokes et al. (1989) suggested that this anti-phase pattern in the trunk helps to reduce the rotational momentum of the body and furthermore, may help to achieve a smoother gait pattern.

Murray et al. (1978) observed that at self-selected speeds, people with Parkinson's moved the pelvis and thorax in the transversal plane more in-phase as compared with control subjects. Recent research suggests this in-phase pattern may be due to rigidity in the trunk. For instance, Huang et al (2010) state that to account for a lack of rotation in the trunk, people with Parkinson's may subsequently move slower, take smaller steps, or adapt pelvic-thorax coordination patterns.

Research suggests that dance can help improve mobility, flexibility, and increase range of motion in the joints (Heiberger et al., 2011; Earhart, 2009). As rigidity resulting in reduced range of motion is a cardinal symptom of Parkinson's and may be hindering trunk coordination, there is a need to look more closely at changes to these variables in the context of gait analysis. Reduced range of motion in the trunk may also be connected to poor posture, difficulties with turning, as well as decreased step and stride length.

Cross correlation has been used to study the coordination between movements of different parts of the body (Shum et al., 2007; Lee and Wong, 2002; Crosbie et al., 2013; Nelson-Wong et al., 2009). This method studies the correlation between two different signals at different time lags. The correlation coefficient (otherwise known as the 'r' value) measures how similar or opposing the two signals are at a given time lag. At zero lags a coefficient value closer to 1 shows that the two signals are more in-phase whereas a coefficient value closer to -1 shows that the two signals are moving in a more anti-phase pattern. The

coefficient values and their respective time lags are therefore a useful tool for measuring coordination patterns between two parts of the body in motion.

This chapter outlines the potential benefits of weekly ballet sessions on trunk coordination and range of motion during gait for people with Parkinson's. Ballet places a strong emphasis on whole-body coordination and engagement of postural muscles to maintain proper alignment. It is a form of dance that can challenge one's strength, stability, and range of motion and thus may have the potential of improving axial rotation and trunk coordination during gait.

5.2 Methods

5.2.1 Participants

A total of 19 people diagnosed with Parkinson's who volunteered to take part in weekly ballet classes were analysed for these measures. A total of 13 people also with Parkinson's who were asked to not participate in dance classes across the duration of the study formed the control group.

Table 2.1 Participant Characteristics at Onset of Study

	Age	Gender	Years Diagnosed	Stage of Parkinson's	UPDRS Motor Subscale Score	MMSE score
Experimental Group	69.42 ± 4.55	10/9 (F/M)	6.47 ± 2.95	2.32 ± 0.48	29.42 ± 9.11	28.37 ± 1.57
Control Group	73.25 ± 8.09	7/6 (F/M)	5.92 ± 4.13	2.15 ± 0.55	31.69 ± 10.31	28.23 ± 1.64

5.2.2 Data Collection

Two inertial sensors were placed on the upper and lower spine (T1 and S2 respectively) and secured with double-sided tape. Angular displacement data (gathered at a rate of 180Hz) in the transverse plane was not only used to understand the coordination patterns between the pelvis and thorax but also provided insight into range of motion in the upper and lower trunk.

Participants were asked to walk for 10 metres at a self-selected, natural walking speed. Each participant carried out 3 trials in total at each testing point.

5.2.3 Data Analysis

Five stride cycles were analysed from the middle of each data set with the first and last cycles avoided where possible. Prior to determining the five cycles for analysis, the vertical acceleration data was resampled using a fifth order low pass Butterworth filter in Matlab. The cycles were determined by using the vertical acceleration signals to locate heel strikes (Evans et al., 1991).

The cross-correlation coefficient was determined using Matlab (Mathworks, 2015). The time lag between the pelvis and trunk motion was determined as percentage of gait cycle. When the two signals have a strong positive correlation at a point closer to 0%, the coordination pattern can be classified as more in-phase.

The maximum and minimum angular displacements, and the range of motion for each stride were determined (maximum values represented movement of the pelvis/thorax in one direction and the minimum values represented movement in the opposing direction).

5.2.4 *Statistical Analysis*

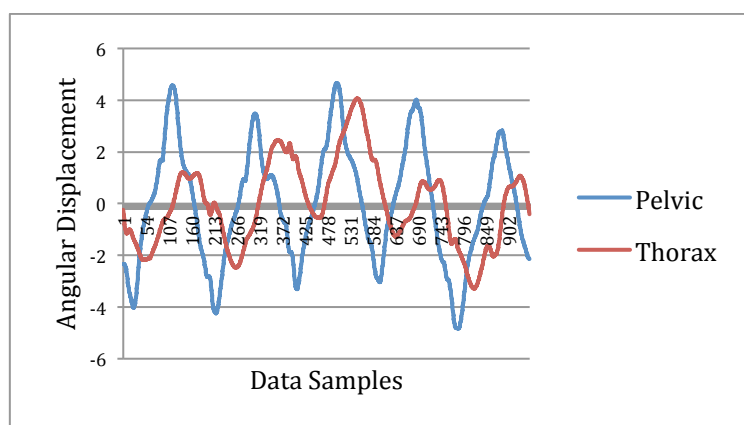
As seen in the previous chapter, normality tests showed that the data sets did not have normal distributions and thus non-parametric statistics were applied. To calculate changes across time in both dancing and control groups the Friedman test was applied. Mann Whitney U tests were used to calculate differences between groups at baseline, short term, and long-term time points. A Spearman Rank Correlation assessed the relationship between trunk coordination and range of motion in the pelvis and thorax. All statistical tests were carried out in SPSS with a significance level set at $p < 0.01$.

5.3 Results

5.3.1 *Initial Analysis of Motion-Time Curves*

Figure 3.1 below demonstrates an example of a motion-time curve from the present study. In this example the two motion signals do not appear to completely oppose one another but rather are coordinating in a more in-phase pattern.

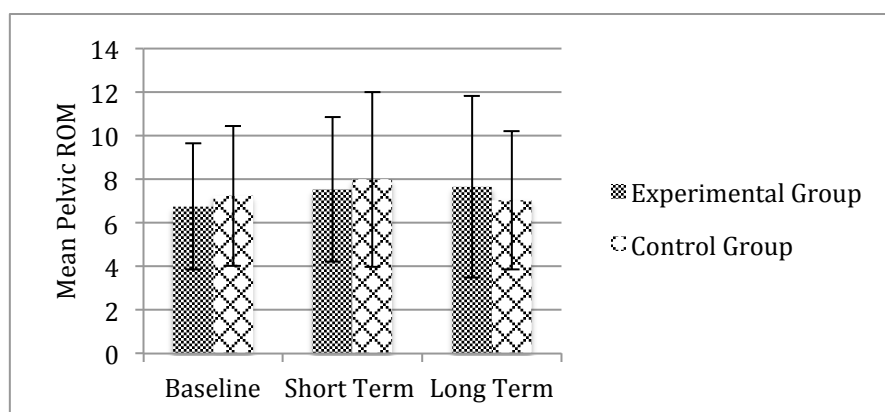
Figure 3.1 Example of a Motion-Time Curve



5.3.2 Pelvic Range of Motion (ROM)

Figure 3.2 presents the changes in pelvic ROM across time for both dancing and control groups. The dancing and control groups did not evidence any significant change across the duration of the study with respect to pelvic ROM ($p=0.105$ and $p=0.273$ respectively). There were also no significant differences between groups with respect to ROM in the pelvis (baseline ($p=0.933$), short term ($p=0.32$), long term ($p=0.355$)).

Figure 3.2 Changes in Mean Pelvic Range of Motion

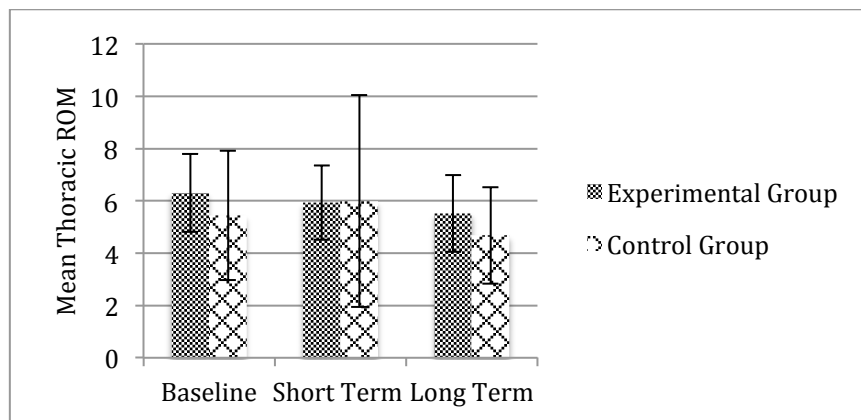


*Error bars represent standard deviation values

5.3.3 Thoracic Range of Motion (ROM)

Figure 3.3 presents change in thoracic ROM across time for both dancing and control groups. There were no significant changes across time with respect to thoracic ROM for either the dancing or control group ($p=0.92$ and $p=0.15$ respectively). There were also no significant differences between groups at various time points (baseline ($p=0.117$), short term ($p=0.122$), long term ($p=0.15$)).

Figure 3.3 Changes in Mean Thoracic Range of Motion



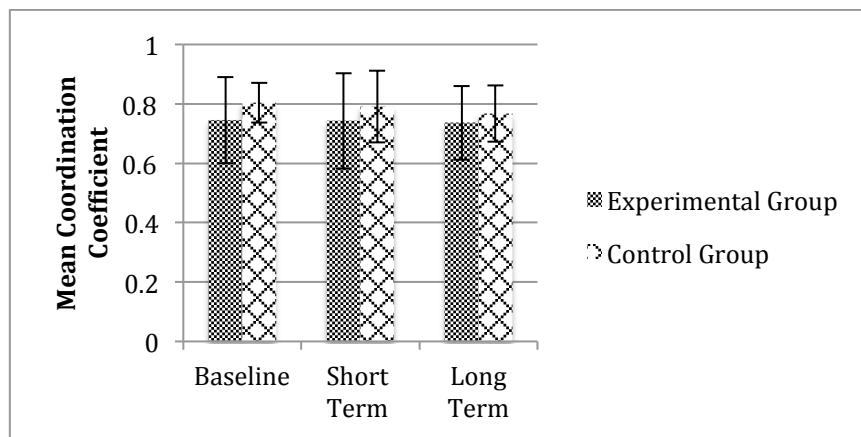
*Error bars represent standard deviation values

5.3.4 Coordination of Movements in Upper and Lower Trunk

Figure 3.4 presents changes in coordination coefficients across time for both dancing and control groups. The dancing and control groups did not show any significant change across the duration of the study with respect to similarity of movements in the upper and lower trunk ($p=0.368$ for both groups). There were also no significant differences between groups across all testing points with

regards to this similarity index (baseline ($p=0.368$), short term ($p=0.822$), long term ($p=0.837$)). These results indicate that the degree of similarity between movements in the upper and lower trunk did not significantly change across the study.

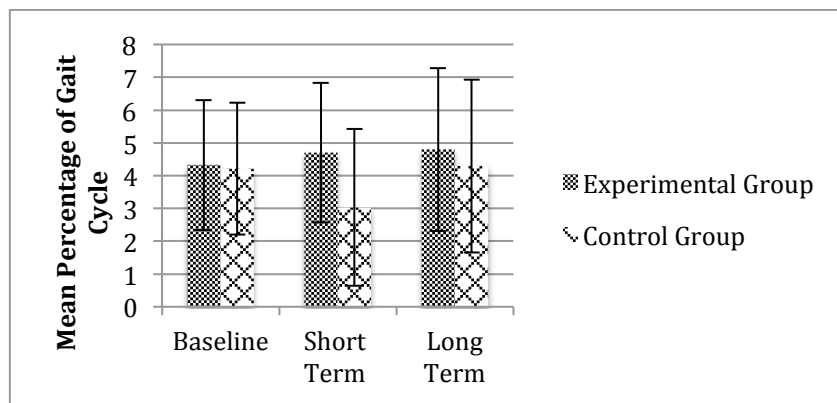
Figure 3.4 Changes in Mean Coordination Coefficient Values



*Error bars represent standard deviation values

Figure 3.5 presents changes in time lag across time for both dancing and control groups. There were no significant changes in gait cycle lag across the duration of the study for the dancing group ($p=0.779$) or the control group ($p=0.122$). There were also no significant differences between groups across all testing points (baseline ($p=0.611$), short term ($p=0.138$), long term ($p=0.837$)).

Figure 3.5 Change to Gait Cycle Lag



*Error bars represent standard deviation values

As the degree of similarity and gait cycle lag did not significantly change across the study, these results indicate that coordination patterns in the trunk did not significantly change as a result of the weekly ballet classes.

5.3.5 Correlations Between Trunk coordination and Range of Motion

There was a significant negative relationship between changes in gait cycle lag and thoracic range of motion in the short term ($r=-0.489$, $p=0.007$). There were no other significant correlations in the short term. There were also no significant correlations between measures of trunk coordination and range of motion in the long term.

5.4 Discussion

This study assessed changes in trunk coordination and range of motion during gait for people with Parkinson's after 12 months of weekly ballet sessions.

Research has shown that healthy gait patterns show an opposing, anti-phase coordination pattern in the trunk while pathological gait has shown trends towards a more in-phase pattern (Murray et al., 1978; Wagenaar and Van Emmerick, 1994; Van Emmerick and Wagenaar, 1996).

The present study found no significant change across time and no significant differences between groups with respect to trunk coordination and range of motion during gait. Analysis of the time lag data demonstrated that the correlation values were strongest for both groups at less than 10% of the gait cycle. This suggests that subjects in both groups were walking with the trunk almost in phase, that is, the trunk and pelvis were moving together due to the rigidity of the trunk.

With regards to correlations between measures of trunk coordination and range of motion during gait, a significant negative correlation was found between the time lag and range of motion in the thorax during gait. However, this negative relationship was weak ($r=-0.489$) and not seen in the long-term results. This implies people with better trunk mobility in the thorax walked with a more in-phase pattern, but such correlation may need to be further established in future research and the physiological implication is unclear.

Recent research has shown that changes in coordination patterns can occur as a result of walking speed. Van Emmerik et al. (1999) observed a change in thorax–pelvis coordination as a function of walking velocity in healthy subjects. As walking velocity increased, pelvis–thorax coordination shifted from more or less

in-phase to more anti-phase (Van Emmerik et al., 1999). As people with Parkinson's often demonstrate a decreased walking velocity, it could be that the participants' self-selected walking speeds were too slow to assume the anti-phase coordination patterns. However, participants may be walking slowly to account for increased axial rigidity (Van Emmerik et al., 1999). Further investigation is needed to better understand the relationship between axial rigidity, a reduced walking speed, and trunk coordination during gait for people with Parkinson's.

Previous dance for Parkinson's research and experience in the field suggests that class participants, as well as observers often note a distinct change in the fluency and coordination of participants' gait (Marchant et al., 2010; Hackney and Earhart, 2009a). Given the nature of these observations, the lack of significant change in the present study may seem contradictory. However, the present study used different parameters (cross-correlation) to assess coordination and looked at trunk coordination in particular, rather than arm and leg coordination. Additionally, when walking during a dance class the participants were often moving to a strong, steady rhythm provided by the musical accompaniment. The music along with the verbal cues from instructors, which were not present during the testing sessions, might influence how participants walk in the dance class.

As discussed previously in this thesis, participants took part in once-weekly ballet classes across the duration of the study. Previous studies have generally had a dance class frequency of at least two to three classes per week with some studies looking at more intensive dance training three to five times a week (Hackney et al., 2007; Duncan and Earhart, 2012; Marchant et al., 2010;

Hackney and Earhart, 2009a). The present study found no significant improvements for trunk coordination and range of motion during gait after 12 months of weekly ballet sessions. It is unknown what the results would be if the dance class frequency was increased and thus further investigation is needed (Lopololo et al., 2006).

Many participants in the present study had been participating in ballet classes for at least one year prior to baseline measurement. As discussed in Chapter Four, the results may reflect the physical plateau that happens when there is a lack of overload on the body system (Power and Clifford, 2013). The ballet class incorporated practice of many functional movements including rotation in the trunk and walking with verbal cues encouraging participants to stride out. While research suggests that these functional movements are useful tools in the rehabilitation for people with Parkinson's (Tomlinson et al., 2012; Goodwin et al., 2008; Keus et al., 2007), it is possible that the participants were not carrying out these movements often enough and with an appropriate amount of overload to induce the physical changes.

5.5 Chapter Summary

The results from the present study demonstrate no significant changes in trunk coordination and range of motion during gait after 12 months of weekly ballet classes for a group of people with Parkinson's. While the ballet classes incorporated practice of functional movements that have shown to be useful in other rehabilitation programmes for this group of people, it is possible that the

movements were not carried out often enough and with the appropriate amount of overload to elicit any potential positive change. It remains to be demonstrated whether improvements in coordination could be achieved with an increased ballet class frequency and thus further investigation is needed.

Future research should continue to assess potential changes in trunk coordination with increased ballet class frequency and the impact these changes may have on activities of daily living. Furthermore, there is a need to understand the mechanisms of change with regards to ballet for people with Parkinson's and if/how specific movements are impacting upon functional mobility. It would be useful to understand other psychosocial benefits of ballet for this population. While this chapter focused on gait specifically, participation in the ballet classes may have provided other benefits, as the thesis will go on to discuss.

Chapter Six

Impact of a ballet intervention on daily living and motor impairments in people with Parkinson's

6.1 Introduction

As discussed in previous chapters, fear of falling is often a main cause of withdrawal from participation in activities and within the community for people with Parkinson's (Schaafsma et al., 2003; Hausdorff, 2009; Earhart, 2009). Foster et al. (2013) suggest that the lack of ability to carry out everyday tasks with ease and efficiency may lead to a loss of independence and a subsequent reduced quality of life (Rahman et al., 2008; Schrag et al., 2000), as well as substantial socioeconomic costs (Huse et al., 2005). While dance has shown to be a beneficial activity for people with Parkinson's, there is a lack of research looking at the beneficial effects of ballet for this group of people with much of the research focusing heavily on Tango or other creative dance forms.

The present thesis has proposed a new framework for dance for Parkinson's research that aims to understand how dance is impacting upon an individual's health, their daily activities, and their level of participation in society while also considering personal and environmental contextual factors (see Chapter Two, section 2.8 for further information regarding this framework). Chapter Two suggests that research in the field has primarily focused on how dance can improve physical impairments. However there is a lack of understanding of how those changes impact upon daily activities and life experiences. The Unified Parkinson's Disease Rating Scale (UPDRS) is often used to assess changes in motor impairments (Goetz et al., 2007). However, several studies in the field only include subsection three (the motor subscale) and do not include other

components that focus on changes to activities of daily living (Heiberger et al., 2011; Marchant et al., 2010; Hackney and Earhart, 2009a).

This chapter outlines the effects of weekly ballet classes on experiences of daily living as well as motor impairments across a 12-month period.

6.2 Methods

6.2.1 Participants

A total of 24 participants in the dancing group were analysed for this measure. All control participants (15 in total) were included in the following analysis.

Table 3.1 Participant Characteristics at Onset of Study

	Age	Gender	Years Diagnosed	Stage of Parkinson's	UPDRS Motor Subscale Score	MMSE score
Experimental Group	69.00 ± 4.52	11/13(F/M)	8.88 ± 6.05	2.42 ± 0.58	30.33 ± 9.79	28.5 ± 1.47
Control Group	74.21 ± 7.88	8/7 (F/M)	5.40 ± 4.06	2.20 ± 0.77	33.13 ± 12.02	28.33 ± 1.54

6.2.2 The Unified Parkinson's Disease Rating Scale (UPDRS)

The scale, initially published by Fahn et al. in 1987, was recently revised under the sponsorship of the Movement Disorder Society (MDS) (Goetz et al., 2007). The revised UPDRS consists of 4 parts that assess the severity of non-motor and motor symptoms as well as complications arising from those symptoms. An administrator rates some sections of the scale while other sections form part of a questionnaire to be completed by the participant (either with or without

assistance from a carer). A 5-point rating scale is used throughout with the following categories: Normal (0), Slight (1), Mild (2), Moderate (3), Severe (4).

MDS require that the person who administers the scale take part in an online training course and pass a final exam before entering into a testing situation. A chartered physiotherapist and myself administered the UPDRS scale in the present study and both administrators were qualified to administer the scale prior to collecting data.

Below is a description of the UPDRS subsections with reference to the ICF framework. It is important to note that the UDPRS was not created with the aim of addressing all domains of the ICF. Although the present study aims to categorize the various UDPRS subsections into the ICF framework, there is a need to understand that some subsections may incorporate questions that cross over multiple ICF domains. This issue will be discussed later in the chapter and recommendations for future research will be made.

Part one of the UPDRS consists of 13 questions that assess the severity of non-motor aspects of daily living. Questions in this section ask about difficulties with memory and cognitive functioning, feelings of depression and anxiety, sleep disturbances, pain sensations, and difficulties with urinary and bowel functions. As this subsection focuses on impairments of body functions or structures, previous research has categorized this subsection under the first domain of the ICF framework (Dibble et al., 2010). The present study also suggests that questions within this subsection are representative of the first domain in the ICF.

Part two consists of 13 questions that assess the severity of motor aspects of experiences of daily living. Questions in this section ask participants about difficulties with speaking, eating, dressing, maintaining personal hygiene, walking and taking part in hobbies. With a primary focus on difficulties that participants may face in carrying out daily activities, the majority of questions are more representative of the second domain in the ICF framework. However, some questions, such as difficulties with excess saliva and drooling or severity of tremor, appear to be more representative of the first domain of the ICF. For the context of the present study, this subsection represents issues under the second domain of the ICF (Dibble et al, 2010).

Part three consists of 33 tasks that are rated by an administrator to assess the severity of motor impairments. For the context of this study, information gathered from this particular subsection will provide insight into the function or structure of the body and thus more closely represent the first domain of the ICF framework (Dibble et al., 2010; Ellis et al., 2011).

Part four consists of six questions that ask about motor complications often stemming from symptoms and anti-Parkinson's medications. This subsection is rated by the administrator and asks about difficulties with dyskinesia, 'on' and 'off' states (when medications are working properly and when they are not), and painful dystonia. Though often not included in intervention studies, this subsection appears to be more representative of the first domain of the ICF as it focuses on difficulties with body functions.

6.2.3 Data Analysis

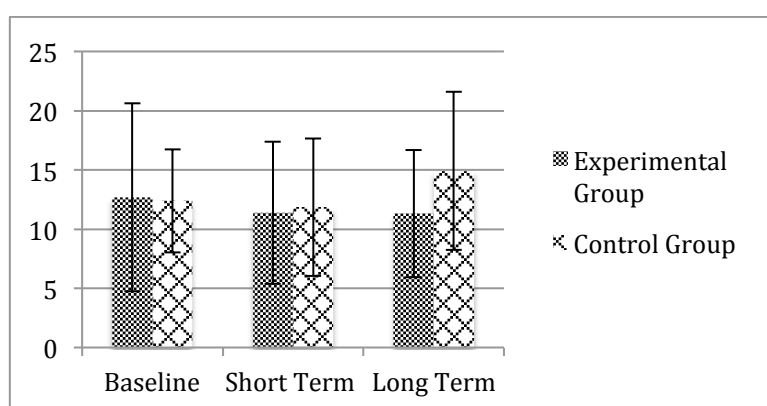
UPDRS data was analysed across the short term (3-5 months) and across the long term (10-12 months). Total scores were added up for each subsection of the scale and dealt with separately to allow the researchers to distinguish between the various domains. As normality tests demonstrated non-normal distributions, non-parametric tests were used. For each separate subscale, the Friedman test was used to calculate changes across time in the dancing group and in the control group. To calculate differences between groups at each of the three time points (baseline, short term, and long term) a Mann U Whitney test was applied. A Spearman Rank Correlation was used to assess the relationship between the various subscales. All statistical tests were carried out in SPSS with a significance level set at $p < 0.01$.

6.3 Results

6.3.1 UPDRS Part One

Figure 4.1 presents the changes in non-motor aspects of daily life experiences across time for both dancing and control groups. The dancing and control groups did not show any significant change across the duration of the study with respect to non-motor aspects of daily living ($p=0.634$ and $p=0.127$ respectively). There were also no significant differences between groups with respect to non-motor aspects of daily life experiences (baseline ($p=0.633$), short term ($p=0.950$), long term ($p=0.086$)).

Figure 4.1 Changes in Non-Motor Aspects of Daily Living



* Error Bars represent standard deviation values

Table 3.2 below displays the mean changes in UPDRS part one scores across the duration of the study for both dancing and control groups.

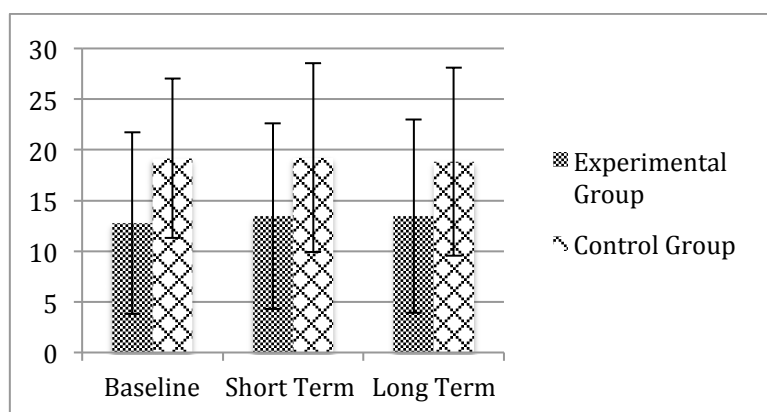
Table 3.2 Mean Changes in Non-Motor Aspects of Daily Living

	Baseline Mean (SD)	Short Term Mean (SD)	Long Term Mean (SD)
Experimental Group	12.68 (7.94)	11.37 (5.99)	11.32 (5.38)
Control Group	12.38 (4.35)	11.85 (5.80)	14.92 (6.69)

6.3.2 UPDRS Part Two

Figure 4.2 presents the changes in motor aspects of daily life experiences across time for both dancing and control groups. The changes across the duration of the study were non-significant for both groups ($p=0.252$ and $p=0.763$ respectively). There were also non-significant differences between the two groups at various time points (baseline ($p=0.085$), short term ($p=0.204$), long term ($p=0.104$)).

Figure 4.2 Changes in Motor Aspects of Daily Living



* Error Bars represent standard deviation values

Table 3.3 below displays the mean changes in UPDRS part two scores across the duration of the study for both dancing and control groups.

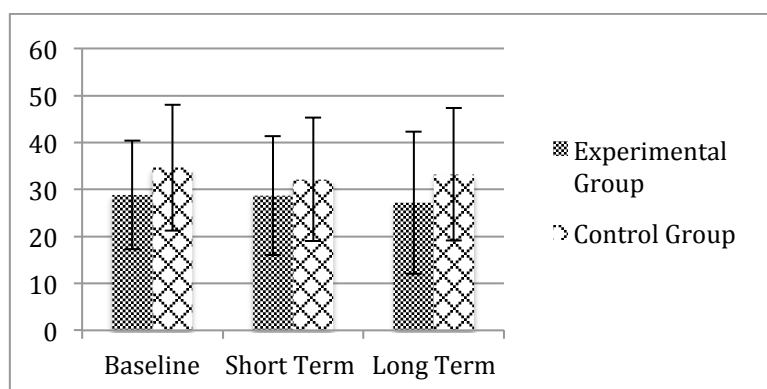
Table 3.3 Mean Changes in Motor Aspects of Daily Living

	Baseline Mean (SD)	Short Term Mean (SD)	Long Term Mean (SD)
Experimental Group	12.78 (8.97)	13.44 (9.17)	13.44 (9.53)
Control Group	19.15 (7.86)	19.23 (9.33)	18.85 (9.29)

6.3.3 UPDRS Part Three

Figure 4.3 presents the changes in motor impairments across time for both dancing and control groups. There were no significant changes across time with respect to motor impairments for either the dancing or control ($p=0.525$ and $p=0.472$ respectively). There were also no significant differences between groups at baseline ($p=0.279$), short term ($p=0.471$), or long term ($p=0.218$).

Figure 4.3 Changes in Motor Impairments



* Error Bars represent standard deviation values

Table 3.4 below displays the mean changes in UPDRS part three scores across the duration of the study for both dancing and control groups.

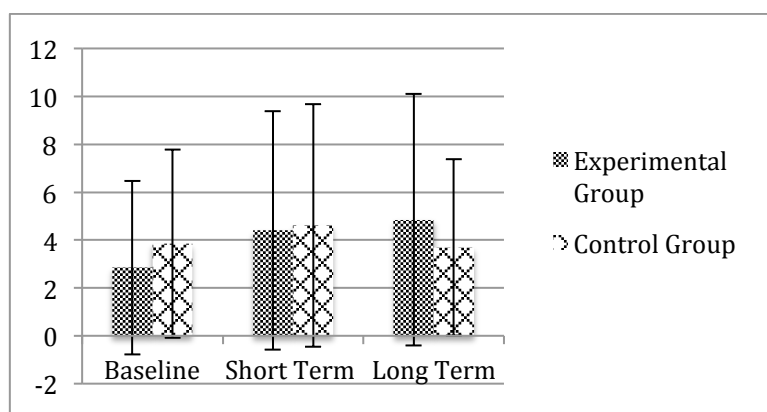
Table 3.4 Mean Changes in Motor Impairments

	Baseline Mean (SD)	Short Term Mean (SD)	Long Term Mean (SD)
Experimental Group	28.85(11.55)	28.7 (12.65)	27.15 (15.12)
Control Group	34.62 (13.38)	32.15 (13.13)	33.23 (14.08)

6.3.4 UPDRS Part Four

Figure 4.4 presents the changes in motor complications across time for both dancing and control groups. The two groups did not evidence any significant change with respect to motor impairments across time (dancing group ($p=0.084$) and control group ($p=0.407$)). There were also no significant differences between groups at the various time points (baseline ($p=0.927$), short term ($p=0.91$), long term ($p=0.986$)).

Figure 4.4 Changes in Motor Complications



* Error Bars represent standard deviation values

Table 3.5 below displays the mean changes in UPDRS part four scores across the duration of the study for both dancing and control groups. It is important to note the relatively high standard deviation values below. While some participants within this study struggled with motor complications such as dyskinesia and distinct “on” and “off” states, many participants did not struggle with these issues and thus reported a score of 0 for the subsection.

Table 3.5 Mean Changes in Motor Complications

	Baseline Mean (SD)	Short Term Mean (SD)	Long Term Mean (SD)
Experimental Group	2.85 (3.63)	4.4 (4.98)	4.85 (5.25)
Control Group	3.85 (3.93)	4.62 (5.08)	3.69 (3.68)

6.3.5 Correlation between UPDRS Subscales

Short term

There was significant moderate correlation between parts one (non-motor aspects of daily living) and two (motor aspects of daily living) of the UPDRS scale

($r=0.416$, $p=0.01$). There was also a significant negative correlation between parts one and three (motor impairments) of the UPDRS scale ($r=-0.655$, $p=0.000$). There were no other significant correlations in the short term.

Long Term

There was significant moderate correlation between parts two (motor aspects of daily living) and three (motor impairments) of the UPDRS scale ($r=0.441$, $p=0.01$). There were no other significant correlations in the long term.

6.4 Discussion

The results show that participation in a weekly ballet class did not have a significant effect on experiences of daily living or motor impairments for this group of people. However, it may be argued that when the sample size is relatively small with high levels of variability the statistical tests might not have sufficient power to evidence potential change.

Recent research has attempted to determine the minimal clinically important change (MCIC) for various subsections of the UPDRS scale. Schrag et al. (2006) determined the first estimates to define clinically important change in the UPDRS activities of daily living (ADL) and motor subscales. A change of five points on the motor subscale was found to be the most appropriate ‘cut-off’ score for participants at Hoehn and Yahr (H&Y) stages one to three. A change between two and three points was found to be the most appropriate cut-off score for the ADL subscale (UPDRS part two) (Schrag et al., 2006).

Shulman et al. (2010) determined the following reasonable estimates for MCICs on the motor subscale: 2.5 points (minimal change), 5.2 (moderate change), and 10.8 (large change). These authors highlight a controversy about whether the MCIC is more applicable to interpretation at a group level or an individual level. These authors suggest the range of values demonstrated in their study may help to meet the needs of varying situations. For instance, the use of minimal to moderate MCIC values may be more applicable when interpreting group differences and moderate to large values may be more applicable to individual differences (Shulman et al., 2010).

In a recent study, Hauser et al. (2014), discuss varying results for the MCICs depending on severity of condition. In early Parkinson's disease (EPD) the MCICs for UDPRS part two were found to be -1.8 and -2.0 depending on which dopamine agonist the participants were taking. For UPDRS part three the MCICs were -6.2 and -6.1, again depending on whether participants were taking an extended release or immediate release dopamine agonist. For advanced Parkinson's disease the values for MCIC in UPDRS part two were -1.8 and -2.3 and in UPDRS part three were -5.2 and -6.5 respectively. These authors conclude that a wide range of MCICs are emerging in recent literature and that differences may depend on many factors including study design and efficacy of intervention in determining the MCIC values (Hauser et al., 2014).

Based on the above estimates, the present study found no clinically meaningful changes in the UPDRS part two or UPDRS part three scores for both dancing and control groups. Functional movements seen within the ballet class including

reaching, twisting, bending, walking, balancing, and transfers of weight have all been noted as useful tools in physical rehabilitation regimes for people with Parkinson's (Tomlinson et al., 2012; Goodwin et al., 2008; Keus et al., 2007). As discussed in earlier chapters, while the actions and exercises involved in this ballet class could help alleviate Parkinson's symptoms, it may be possible that the once weekly sessions were not enough to elicit physical change in the short and long term. Although recent research in the field suggests that dancing can help improve motor control, these studies often have a dance class frequency of at least two to three classes per week (Marchant et al., 2010; Hackney and Earhart, 2009a). Furthermore, the present study included dancing participants who had been participating in ballet classes for at least three months prior to baseline measurement with many participants having danced longer before the onset of the study. As such, the results may reflect a lack of physiological overload on the body system needed to avoid physical plateau and encourage progression. However, the present study cannot confirm whether this factor influenced results of the UPDRS. It is also unclear how the UPDRS would be affected with an increased ballet class frequency and thus further investigation is needed.

The present thesis argues that by looking at changes from different perspectives using the ICF framework, researchers can draw stronger, more meaningful conclusions about the potential impact dance is having on people with Parkinson's. While several articles in the field have shown that dance can help improve motor impairments, few studies look at how these changes impact upon the participants' daily lives outside of the studio.

Within the context of the present study, we observed a significant positive correlation between motor experiences of daily living and motor impairments in the long term. As such, this study shows that difficulties with motor impairments were significantly related to motor aspects of daily activities. It is interesting to note the significant inverse relationship between non-motor and motor impairments. This finding suggests that the two kinds of impairments can exist and operate differently within the individual. However, this result was only seen in the short-term and thus further investigation is needed to substantiate these conclusions in the long term.

Alongside the administration of the UPDRS scale, qualitative notes were taken regarding personal contextual factors that may have influenced the results. For instance, one participant made note of cellulitis in the hand that was hindering his ability to perform tasks seen in the motor subscale. When asked about aspects of mental and emotional health some participants confided in the administrator and explained difficulties they were experiencing at home, outside of the dance context. The present thesis argues that these personal contextual factors are important to consider as they may affect how the individual engages with the dancing and how they perform in testing sessions. However, the UPDRS scale does not allow for consideration of these aspects. Future research should continue to gain an understanding of participant experiences both inside and outside of the dance context and should consider these factors when reflecting on the results.

It is important to note that while part two of the UPDRS primarily focuses on activities of daily living, some items appear to be more representative of problems with body functions such as changes to tremor, saliva, and drooling. The difficulty lies in the way the questions are posed and what they each aim to address. For instance, although these items appear to be more reflective of problems with body functions (first domain of ICF), the questions themselves are asking participants about how these problems are affecting daily activities and social interactions (second domain of ICF). As a result, they have been placed in a UPDRS subsection that focuses on activities of daily living even though they are not asking about a particular task or activity. If we look at tremor specifically, part two of the UPDRS asks the participant about how this problem affects daily activities, whereas an administrator in part three of the UPDRS rates the severity or amplitude of this problem. The former example represents the second domain of the ICF whereas the latter represents the first domain.

It would be interesting to understand if participants were gaining any additional benefits from the ballet-based sessions that could potentially lead to increased participation in society and in the community. Studies in the field have suggested that participation in dance classes can have a positive effect on mood, motivation, socialization, and quality of life factors (Heiberger et al., 2011; Westheimer, 2008). However, few studies to date have looked at how dance may impact upon participation in society (Foster et al., 2013). The following chapter will focus on these issues in more detail.

6.5 Chapter Summary

The results from the present study demonstrate no significant changes in impairments and activities of daily living after 12 months of weekly ballet classes for people with Parkinson's. There was a significant positive correlation between motor impairments and activities of daily living in the long term.

Future research is required to provide more definitive evidence on potential changes in physical and mental impairments alongside activities of daily living after participation in dance-based interventions. This is due to small sample size of the groups, and the fact that the current ballet programme was limited to one class per week.

With reference to the ICF framework, it would be useful to understand how participation in dance-based activity may help to encourage participation in the wider community and in society for this group of people. The present study applied the ICF framework to the commonly used UPDRS and found that there was need to explain how the various subscales reflected domains within the ICF. When using the ICF future research should make clear how the chosen methods of assessment help to gain information about the various ICF domains.

Chapter Seven

Effects of a 12-month ballet-based dance intervention on aspects of participation for people living with Parkinson's

7.1 Introduction

Alongside physical improvements, people with Parkinson's have shown improvements in mood, motivation, and general sense of health and wellbeing after taking part in dance classes (Hashimoto et al., 2015). Furthermore, as discussed in earlier chapters, adherence to this particular form of physical activity has been strong among studies in the field demonstrating that many have found this activity to be enjoyable and beneficial (Hackney et al., 2007; Hackney and Earhart, 2010a; 2010b; Volpe et al., 2013).

Schrag et al. (2000) sought to determine factors that contribute to quality of life for people with Parkinson's. Findings suggested that depression, disability, instability, and cognitive impairment had the greatest influence on quality of life for those with Parkinson's. The authors concluded that improvement in the severity of these issues should therefore become an important target in treatment regimes. The present thesis has argued that recent research in the dance for Parkinson's field has placed a strong emphasis on assessing changes to the physical impairments after dance interventions. While this information is of great importance, there is a need for research to understand how these physical and mental changes are impacting upon activities of daily living and participation in society (McGill, Houston, and Lee, 2014).

Although individuals in the early stages of Parkinson's may not experience motor dysfunction that is sufficient enough to cause physical disability, recent research has still shown reduced participation in low physical-demand leisure

and social activities (Foster and Hershey, 2011; Foster et al., 2013). Thus, it appears that reduced participation is not solely due to physical impairments and there are other important factors that play an important role in maintaining levels of participation. As participation has shown to be associated with life satisfaction and health-related quality of life (Everard et al., 2000; Duncan and Earhart, 2011; Yeung and Towers, 2014; Levasseur et al., 2008), research should focus on identifying alternative treatment options and physical activities that help to improve participation in society, thus also improving quality of life factors.

Foster et al. (2013) discuss participation with reference to the World Health Organization's (WHO) International Classification of Functioning, Disability, and Health (ICF). This thesis has proposed the use of the ICF as a potential framework for future dance for Parkinson's research (McGill, Houston, and Lee, 2014). As discussed in Chapter Two, section 2.8, within the ICF participation is described as involvement in life situations and participation restriction as problems an individual may experience in involvement in life situations. In this context life situations may include social interactions, involvement in the surrounding community, and one's ability to contribute to society (WHO, 2001; 2002). Though participation may also be discussed in relation to continuing participation (adherence) to the dance classes, for the purposes of the present study participation will be discussed in relation to life situations outside of the dance context.

Duncan and Earhart (2011) found a strong, negative correlation between overall quality of life, as measured by the PDQ-39, and participation in activities, as

measured by the Activity Sort Card (ACS). A lower score on the PDQ-39 is representative of a better quality of life whereas a higher score on the ACS is representative of increased activity participation. Overall the study showed that those with reduced quality of life participated less in a wide range of activities.

Foster et al. (2013) presented the first study to assess the effect of a dance intervention on activity participation in this population. A total of 52 participants with Parkinson's were randomly assigned to the Argentine Tango group or to a control group with no intervention. Amongst other physical measures, the researchers followed on from work by Duncan and Earhart (2011) utilizing the Activity Card Sort (ACS) to assess perceived level of participation in daily life activities. The ACS consists of 89 cards containing pictures of people involved in activities that fall into one of four domains: (1) Instrumental activities (2) Low-demand Leisure activities (3) High-demand Leisure activities and (4) Social activities. The Tango group reported increased activity participation over the course of the study whereas participation in the control group remained relatively stable. Across the separate domains, low-demand leisure activities showed the most consistent improvements in the dancing group.

While their study provided initial support for the efficacy of community-based dance in improving participation, Foster et al. (2013) suggest future research may want to investigate the nature of changes in participation and the relative importance of the various facets of participation to the overall health and well-being of the person with Parkinson's. This recommendation is particularly relevant given their findings that show stronger improvements in low-demand

leisure activities. Examples of low-demand leisure activities within the ACS measure include things like reading, playing table games, and watching television. While there is nothing necessarily wrong with these sorts of activities, one could argue that they are not the best examples of participation in life situations, as defined by the ICF framework. Furthermore, these activities may not help participants to maintain important life aspects such as personal relationships and a sense of independence and self-efficacy. However, upon further analysis and categorization of ACS results, Foster et al. (2013) concluded that the Tango group gained a significant number of New Social Activities whereas the control group did not. As suggested by these authors, further investigation is needed to understand how dance may impact upon the various facets of participation.

There is debate within research regarding the most effective methods to assess quality of life factors that may impact upon activity participation. Chapter Two discussed work by Den Ouden et al. (2011) suggesting that quality of life may be better measured via focus group discussions or interviews that take into consideration the person's own perception of health and wellbeing. Research by Chiong-Rivero et al. (2011) agrees that measures of health-related quality of life should be grounded in qualitative research in order to fully understand the perspectives of persons with the condition. These authors conducted a study investigating the impact of Parkinson's on health status of patients and caregivers using focus group discussions and interviews. Upon analysing the findings the authors suggest that establishing a sense of order and routine in patients' lives may help to reduce feelings of anxiety and uncertainty. The inclusion of

therapeutic activities such as Tai chi and Yoga is recommended as a possible way to help mitigate the physical and emotional burden of the condition. Furthermore, creating and maintaining a healthy social network of family and friends can also aid in reducing uncertainty and improve quality of life (Chiong-Rivero et al., 2011).

With regards to questionnaires that assess quality of life aspects, a number of issues may develop. For instance, the set questions and responses presented to participants in a questionnaire may cause respondents to provide answers that they would not have normally thought of or chosen on their own (Foddy, 1993). Therefore it could be argued that the answers given in a questionnaire are not always the most accurate reflection of participants' perceptions and that participants are being guided to provide an answer even if the given choices do not resonate strongly with them.

Schensul et al. (1999) argue that without a descriptive context, numerical data can have limited meaning. However, it is through statistical analysis of quantitative (numerical) data that researchers can say more about how the results reflect a wider group of people. Schensul et al. (1999) state that, "both quantitative and qualitative data provide the cross-checks (triangulation) that ensure the numerical data are a valid and effective representation of the phenomenon being measured," (pp. 5).

In a recent study investigating the effects of dance on motor function and quality of life among persons with Parkinson's, Westheimer et al. (2015) utilized both

quantitative methods (PDQ-39 and Becks Depression Inventory) and qualitative methods (interviews) to assess changes in quality of life aspects. During exit interviews participants consistently reported positive physical, emotional, and social benefit as a result of participation in the twice-weekly dance sessions across an 8-week period. It is however interesting to note that these positive findings were not seen in the quantitative measures. There were no significant changes from baseline to post-intervention in the PDQ-39 or the Becks Depression Inventory. This finding suggests that the interviews provided additional insight into what participants gained from participating in the dance classes that was not as easily accessible through data collected via questionnaires. As each individual participant will experience the dancing in their own unique way and may value different elements of the class, the interviews allowed for these nuances and differences to be discovered and explored (Westheimer et al., 2015). While questionnaires can be a useful tool to understand significant changes across a group, it is also important to recognise the individual and their thoughts, opinions, and experiences (McGill, Houston, and Lee, 2014; Houston, 2011).

This chapter aims to understand if the weekly ballet-based dance classes had a positive effect on factors that are associated with perceived quality of life and thus participation levels. Such factors include perceived sense of health (Duncan and Earhart, 2011), perceived severity of symptoms (Foster and Hershey, 2011), level of difficulty with functional tasks (Duncan and Earhart, 2011), levels of confidence and self-efficacy (Ellis et al., 2011; Foster et al., 2013), and perceived levels of interference from illness (Devins, 2010). The present study also uses a

mixed methods approach to access information about changes to quality of life factors. Through this kind of analysis we may be better able to understand how and why dance can have a positive impact upon activity participation.

7.2 Methods

7.2.1 Participants

A total of 15 dancing participants and eight control participants were analysed for the measures within this chapter.

Table 4.1 Participant Characteristics at Onset of Study

	Age	Gender	Years Diagnosed	Stage of Parkinson's	UPDRS Motor Subscale Score	MMSE score
Experimental Group	68.47 ± 4.50	6/9 (F/M)	8.27 ± 5.98	2.4 ± 0.63	29.00 ± 9.55	28.87 ± 0.92
Control Group	76.63 ± 5.55	4/4 (F/M)	4.5 ± 3.42	1.75 ± 0.46	29.88 ± 10.40	28.00 ± 1.85

7.2.2 The Dance for Parkinson's Questionnaire (DPQ)

Cynthia McRae and Robert Rubin created the DPQ in 2011. The questionnaire followed on from previous work by McRae et al. (2004) that looked at the effects of perceived treatment on quality of life for people with Parkinson's. The DPQ has only been used informally and results have not been published in previous research. The questionnaire is a 10-part scale compiled from a number of validated questionnaires used to measure various symptom and quality of life issues for people with Parkinson's. The scale was developed to better understand physical, mental, emotional, and social benefit that people with Parkinson's may

gain from taking part in dance (all forms). Furthermore, the scale aims to understand how participants feel about the dancing experience. It is a self-administered scale and participants are asked to comment on how they feel at their worst.

The first subsection consists of a single question taken from the Short Form Health Survey (SF-36) (Ware and Sherbourne, 1992). This item asks participants to rate on a five-point scale how they would describe their health at the present time. A lower score is representative of better health.

Subsections two and three originate from the patient version of the Unified Parkinson's Disease Rating Scale (Montgomery et al., 1994). The second subsection asks participants to rate on a five-point scale how well they can perform various daily activities when feeling at their worst.

Subsection three asks participants to rate on a five-point scale how severe various symptoms are when feeling at their worst. For these subsections a lower score represents a less severe problem.

Subsection four consists of one global item that has been used in previous Parkinson's research (McRae et al., 2004). This question asks participants to rate on a seven-point scale how free or restricted they feel in doing what they want to do. A lower score represents feeling more free to take part in activities.

Subsection five represents the patient version of the Hoehn & Yahr scale (1967) and asks participants to indicate which stage of Parkinson's most closely resembles their current state. A higher score indicates a more progressed stage.

Subsection six consists of eight questions that were developed from Bandura and Lorig's work on self-efficacy in Parkinson's patients (Bandura, 2006; Lorig et al, 2001). These questions ask participants to rate on a seven-point scale how certain they are about aspects of future life (i.e. having hope for the future, making new friends, continuing to enjoy learning new things). A higher score indicates a stronger level of certainty about being able to continue these aspects of their life.

Subsection seven consists of five questions originating from the Centre for Epidemiologic Studies Depression Scale (CES-D) (Radloff, 1977). Participants are asked to rate on a four-point scale how they felt or acted across the past week. A lower score represented a happier and healthier mood. An additional question was added to this subsection and asked participants to rate how motivated they felt across the past week.

Subsection eight is an abbreviated version of Intrusiveness of Illness scale, (Devins, 2010). The scale consists of seven questions that ask participants to rate on a seven-point scale if they feel their illness (Parkinson's) is interfering with important aspects of their life (i.e. personal relationships, self esteem, and sense of independence). A lower score represents less interference.

Subsection nine is a global item that has been used in other Parkinson's research (McRae et al., 2004) and asks participants to rate on a five-point scale their perceived quality of life at the present time. A lower score represents a better quality of life.

Subsection ten is a dance questionnaire based on work by Quiroga Murcia et al. (2010). This scale consists of 19 questions asking those participants who took part in the dance classes to rate their experiences on a five-point scale.

To my knowledge, this is the first study to utilize the DPQ, though subsections of the scale have been used separately in previous research. The present study will display findings from the first nine subsections that were completed by both dancing and control participants. For this purposes of this study, subsection 10 will not be included in the statistical analysis as only the dancing participants completed this subscale. Instead, the interviews, focus group discussions, and informal conversations will provide detailed information about the dancing experience from the participants' perspective.

7.2.3 Interviews, Focus Group Discussions, and Informal Conversations

The material in this chapter forms part of the wider project between ENB and University of Roehampton (see Chapter Three, section 3.3). In the wider project interviews and focus group discussions were carried out with a large number of participants taking part in the ballet classes at ENB. However, this chapter focuses solely on those participants who carried out initial one-to-one interviews

for this PhD thesis and who also completed the DPQ across the duration of the study.

A total of five dancing participants took part in one-to-one semi-structured interviews at the start of the project. The interviews were conversations with set and spontaneous open questions (see Appendix 11 for full transcription of each interview). Questions centred around participants' perceptions of benefits they were receiving from the dance classes in comparison to other physical activities they were taking part in or had taken part in previously. Furthermore, a set of questions were used to better understand whether participants felt that their Parkinson's was holding them back from participating in daily life roles or participating in the wider community. All interviews were recorded and lasted between 30 and 60 minutes.

The audio files were transcribed verbatim before main themes were drawn out and noted. While the one-to-one interviews took place at the start of the project, all participants had been dancing with ENB for at least one year prior to these discussions.

A total of three out of the five dancing participants who took part in one-to-one interviews also took part in at least one focus group discussion near the end of the study. Questions were based on themes that were brought up in the analysis of interviews (both the one-to-one interviews carried out specifically for this PhD thesis and other interviews conducted by the research team for the wider project). Examples of themes include the importance of the live musical accompaniment,

participation in activities both inside and outside of ballet class, how the ballet classes differed from other activities, the growing sense of a bonded community, and why dancing is important to them. The questions were set but participants were encouraged to discuss these ideas amongst themselves to bring out more nuance. Detailed notes were taken during the discussions and themes were drawn out and noted.

The nature of the present study meant that the researchers were involved and participated in the weekly dance classes, attended theatre performances with the participants, and had informal conversations before and after the dance classes on a weekly basis. For the purposes of this study, any qualitative information reported from informal conversations will be specific to the five individuals who took part in the initial one-to-one interviews, some of whom also took part in focus group discussions. All five individuals completed the DPQ.

Themes were drawn from the interviews, focus group discussions, and informal conversations to provide additional insight into the research questions.

7.2.4 Data Analysis

Data was analysed across a 12-month period. As each subsection represented material from a separate validated questionnaire and also differed with respect to rating scales, each subscale was analysed separately. Total scores were added up and dealt with separately in SPSS to allow the researchers to distinguish between the various scales.

7.2.5 Statistical Analysis

For all variables, the Wilcoxon tests were used to calculate changes across time in the dancing group and in the control group. Mann Whitney U tests were used to calculate differences between groups. A Spearman Rank Correlation was used to assess the relationship between various subscales. All statistical tests were carried out in SPSS with a significance level set at $p < 0.01$.

The following section will display statistical results for subsections of the DPQ. Qualitative data from interviews and focus groups will be considered in relation to the quantitative data later in the discussion section.

7.3 Results

Table 4.2 below provides mean scores and standard deviations for all subscales as well as the statistical outputs from Wilcoxon tests assessing changes across time. Table 4.3 describes statistical outputs from Mann U Whitney tests assessing group differences.

Table 4.2 Changes in DPQ results after 12 months of weekly ballet classes

	Dancing Group			Control Group		
	Baseline	12 months	Wilcoxon Results	Baseline	12 months	Wilcoxon Results
	Mean (SD)	Mean (SD)		Mean (SD)	Mean (SD)	
Subscale 1	2.93 (1.10)	3.0 (1.08)	$z=-1.134, p=0.257$	2.88 (1.13)	3.13 (1.25)	$z=-.707, p=0.48$
Subscale 2	9.53 (7.47)	11.8 (9.28)	$z=-1.859, p=0.063$	11.25 (8.70)	13.0 (6.16)	$z=-0.773, p=0.44$
Subscale 3	11.64 (6.83)	12.86 (7.61)	$z=-1.665, p=0.096$	13.63 (6.74)	13.13 (2.30)	$z=-0.141, p=0.888$
Subscale 4	3.73 (1.44)	3.5 (1.61)	$z=-0.491, p=0.623$	3.875 (1.96)	3.5 (1.60)	$z=-0.408, p=0.683$
Subscale 5	1.93 (1.07)	1.93 (1.07)	$z=-0.520, p=0.603$	2.29 (1.38)	2.25 (0.89)	$z=-0.368, p=0.713$
Subscale 6	40.07 (10.59)	45.07 (9.27)	$z=-1.435, p=0.151$	40.0 (13.10)	36.63 (12.35)	$z=-0.771, p=0.441$
Subscale 7	7.33 (2.94)	8.36 (4.27)	$z=-1.217, p=0.223$	7.63 (3.38)	9.63 (3.58)	$z=-1.897, p=0.058$
Subscale 8	26.21 (10.19)	21.73 (9.27)	$z=-1.981, p=0.048$	24.38 (13.88)	27.38 (11.17)	$z=-0.946, p=0.344$
Subscale 9	2.6 (0.83)	2.79 (0.97)	$z=-1.732, p=0.083$	2.63 (1.06)	3.0 (1.07)	$z=-1.732, p=0.083$

Table 4.3 Differences between groups in DPQ results at Baseline and 12 months

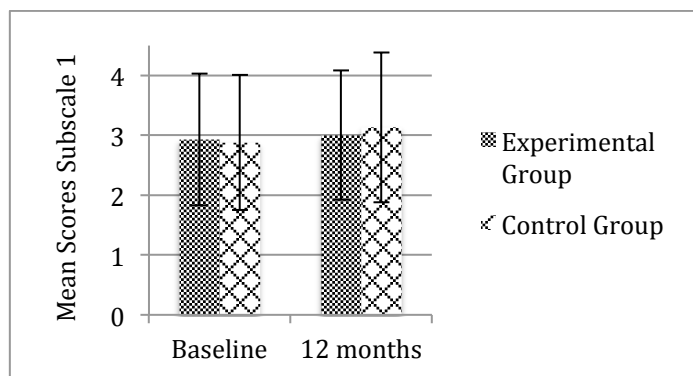
	Mann U Whitney for Group Difference	
	Baseline	12 months
Scale 1	$u=59.5, p=0.973$	$u=47.5, p=0.735$
Scale 2	$u=51.0, p=0.56$	$u=48.0, p=0.438$
Scale 3	$u=43.0, p=0.373$	$u=51.0, p=0.731$
Scale 4	$u=60.0, p=1.0$	$u=55.5, p=0.972$
Scale 5	$u=40.0, p=0.481$	$u=47.0, p=0.51$
Scale 6	$u=55.5, p=0.771$	$u=35.5, p=0.113$
Scale 7	$u=40.0, p=0.481$	$u=47.0, p=0.51$
Scale 8	$u=46.5, p=0.516$	$u=41.5, p=0.232$
Scale 9	$u=59.5, p=0.973$	$u=45.5, p=0.452$

The following results and graphs have been categorized into levels of the ICF framework that best resemble what is being asked of the participant in a particular subscale. The authors of the DPQ did not intend the categorization of these subscales into the ICF domains. However, it will be useful to view the results in this way to better understand the relationship between impairments, daily activities, and participation in life situations.

Subscales one, three, five, and seven ask participants about severity of condition as well as physical and emotional health. These subscales more closely resemble the first domain of the ICF framework that looks at physical and mental impairments. Subscale two asks participants about activities of daily living and thus more closely resembles the second domain of the ICF. Subscales four, six, eight, and nine ask participants about additional factors that are associated with quality of life and thus potential activity participation.

7.3.1 First ICF domain: Body Function and Structure

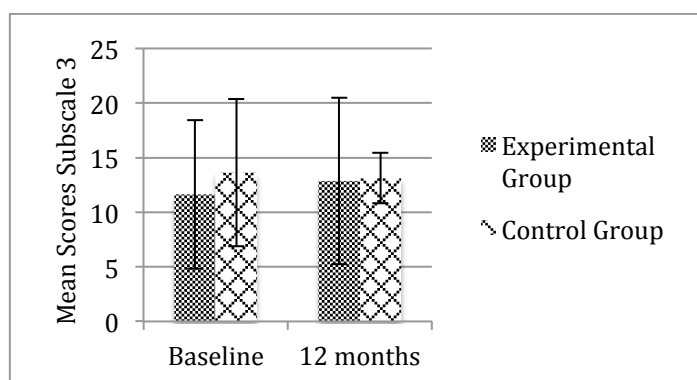
Figure 5.1 Perceived Sense of Health (subscale 1)



* Error Bars represent standard deviation values

There were no significant changes across time or differences between groups with regards to perceived sense of health (please see Tables 4.2 and 4.3 for statistical results).

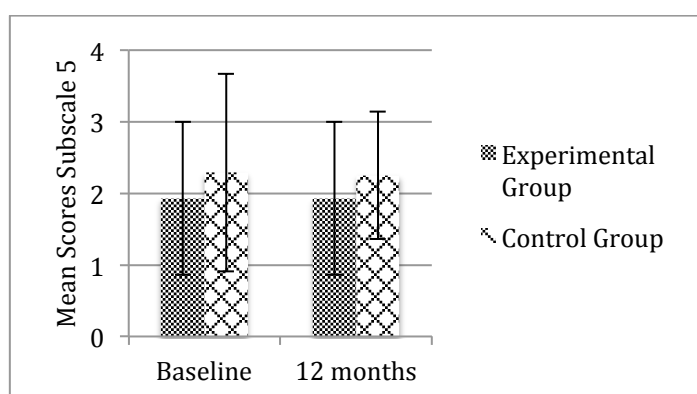
Figure 5.2 Perceived Severity of Parkinson's Symptoms (subscale 3)



* Error Bars represent standard deviation values

There were no significant changes across time or differences between groups with regards to perceived severity of Parkinson's symptoms (please see Tables 4.2 and 4.3 for statistical results).

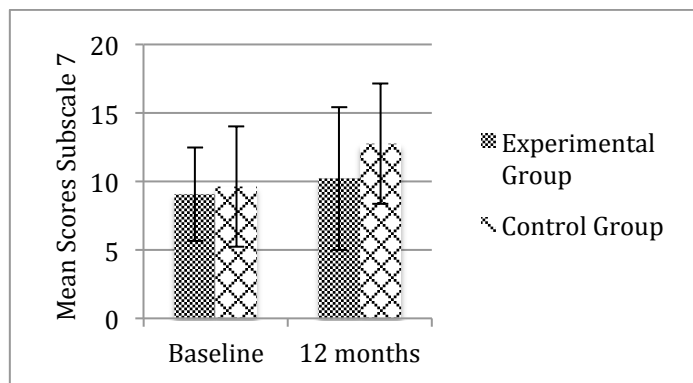
Figure 5.3 Perceived Stage of Parkinson's (subscale 5)



* Error Bars represent standard deviation values

There were no significant changes across time or differences between groups with regards to perceived stage of Parkinson's (please see Tables 4.2 and 4.3 for statistical results).

Figure 5.4 Perceived Emotional Health (subscale 7)

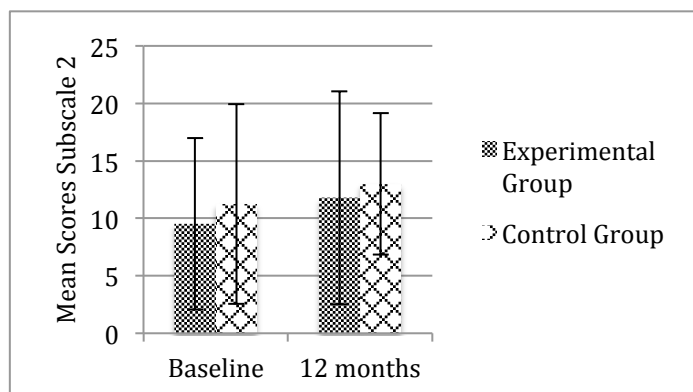


* Error Bars represent standard deviation values

There were no significant changes across time or differences between groups with regards to perceived emotional health (please see Tables 4.2 and 4.3 for statistical results).

7.3.2 Second ICF Domain: Activities of Daily Living

Figure 5.5 Perceived Difficulties with Everyday Activities (subscale 2)



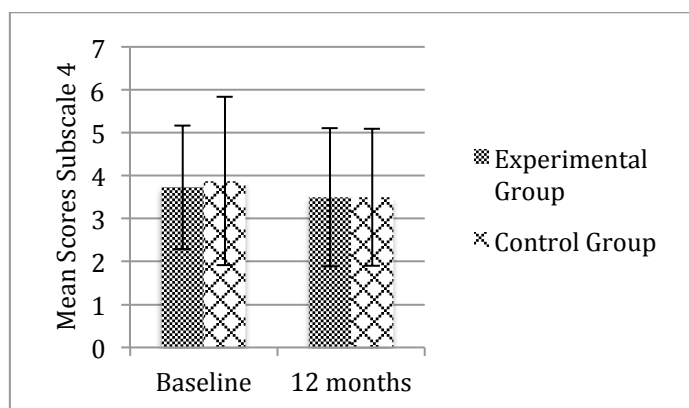
* Error Bars represent standard deviation values

There were no significant changes across time or differences between groups with regards to perceived difficulties with everyday activities (please see Tables

4.2 and 4.3 for statistical results).

7.3.3 Third ICF Domain: Participation

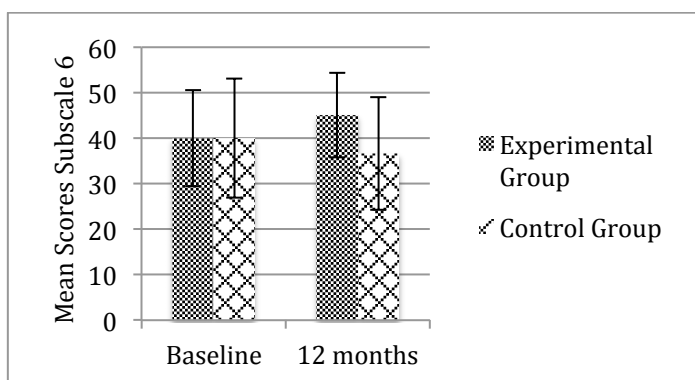
Figure 5.6 Perceived Sense of Freedom (subscale 4)



* Error Bars represent standard deviation values

There were no significant changes across time or differences between groups with regards to perceived sense of freedom (please see Tables 4.2 and 4.3 for statistical results).

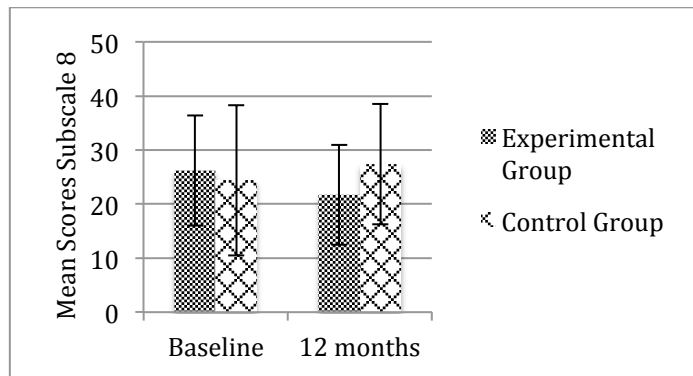
Figure 5.7 Certainty about Aspects of Future Life (subscale 6)



* Error Bars represent standard deviation values

There were no significant changes across time or differences between groups with regards to perceived certainty about future life (please see Tables 4.2 and 4.3 for statistical results).

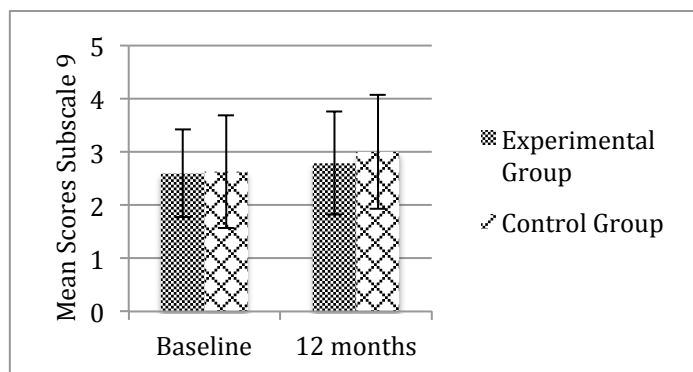
Figure 5.8 Interference of Illness (subscale 8)



* Error Bars represent standard deviation values

There were no significant changes across time or differences between groups with regards to perceived interference of illness (please see Tables 4.2 and 4.3 for statistical results).

Figure 5.9 Perceived Quality of Life



* Error Bars represent standard deviation values

There were no significant changes across time or differences between groups with regards to perceived quality of life (please see Tables 4.2 and 4.3 for statistical results).

7.3.4 *Correlations between DPQ subscales*

There was a significant positive correlation between severity of physical symptoms as rated in subscale three and activities of daily living as rated in subscale two ($r=0.595$, $p=0.004$). There were no other significant correlations between the DPQ subscales.

7.4 Discussion

The present study sought to determine if participation in weekly ballet classes would positively impact upon factors that may influence quality of life and activity participation for people with Parkinson's. While changes to physical impairments were considered, the study also aimed to address other important factors such as difficulties with everyday activities and one's sense of independence and freedom. Rather than assessing participation directly (Foster et al., 2013; Duncan and Earhart, 2011), this study aimed to understand changes to factors associated with quality of life using the Dance for Parkinson's questionnaire (DPQ). As participation has shown to be associated with health-related quality of life in past research (Everard et al., 2000; Duncan and Earhart, 2011), improvement in factors associated with quality of life may impact positively upon participation in life situations.

The present study found no significant changes across time or differences between groups with regards to the nine DPQ subscales. The present thesis has argued for the need to understand how changes to physical impairments impact upon activities of daily living and participation in society for this group of people. Correlation analysis found a significant positive correlation between perceived severity of symptoms and perceived difficulties with everyday activities (the first and second ICF domains respectively). This finding suggests that there is a relationship between impairments and activities of daily living and is supported by findings from Chapter Six noting a similar correlation. However, as there were no significant changes across time or differences between groups within these subscales, it is difficult to describe what these correlation results mean for this group of people.

The lack of significant change across time is particularly interesting when triangulating the DPQ results to other qualitative accounts of perceived changes to physical and mental functioning. Data from one-to-one interviews suggests that all five participants felt the dancing may be doing them some good in relation to improving physical symptoms. However, the specifics of what was happening were sometimes difficult to verbalize.

When asked about what he feels has changed for the better as a result of the dancing, one participant states:

“Yes I think there are two things, one is physical and the other is social.

Physically, as I said before it is hard to distinguish the effect of dance but

I think it does help and quite often it is the non-physical things that are helping as much as anything... I have no doubt it has helped on the good side not the bad side."

When asked the same question another participant mentions:

"Well I suppose slight improvement, slight. You see I had lost my confidence when I got Parkinson's. Afraid to cross over the street you know and even afraid driving, won't go on the motorway, I stay around the spaces that I know. I know that it helps me, as I say, I am much better in some ways."

One participant found it easier to talk about how they thought other people might be physically improving rather than focusing on herself. She states:

"And another thing is that with Parkinson's, people seem to lack coordination to remember that it is the left hand that goes forward when the right foot goes forward. And if you don't give them the music, and you ask them to walk, then they're much more likely to be uncoordinated... so the music gives them better rhythm, better coordination, better speed I think as well."

Although participants think the dancing may be helping them physically, they are not necessarily able to give clear examples of how this has happened for them.

Four participants also noted in their one-to-one interviews that the dance classes were mentally challenging. They suggested that it was quite literally exercise for the brain. However, subscales in the DPQ are not assessing cognitive functioning as much as feelings of depression or happiness. While there was a sense from the interviews that all participants enjoyed the classes, general day-to-day feelings outside of the dance class were not as clearly addressed.

Although statistically insignificant, results from two subscales warrant further discussion. Subscale six saw the dancing participants grow more certain about maintaining a positive future life inclusive of making new friends and developing a community with other Parkinson's people. The control group saw a decline in this particular subscale. This finding suggests that the dancing participants are becoming more confident that they can continue to participate in life situations. Participants in the dancing group also perceived less interference from their illness on important life aspects such as personal relationships and sense of independence after the 12 months. The control group perceived more interference from their illness on important life aspects. Perhaps the dancing has helped participants to find ways to cope better with their condition.

All dancing participants who took part in interviews were keen to stress the importance of the ballet classes as a place where they felt valued and where they could make friends. They reported on how important that bonded community was to their participation in the ballet sessions. The first quote brought forth in the discussion section of this paper demonstrates one participant's view of the main benefits he gained from the ballet classes, including social benefit.

Another participant states:

“... So just to meet with the other people, to enjoy the class is good in itself. And people always seem cheerful when they arrive. And that seems to me to be quite a big part of it, all that. And everybody seems to notice when someone is doing better than usual and they comment upon it, so there is quite a lot of support here for people.”

While another participant states:

“Well I think being together and simple things like as part of dance, I mean it is a way of communicating isn't it. Holding hands for example, moving, looking at someone.”

Though the group setting was important to allow for this bonded community, the actual content and structure of the class allowed for further connection. The content encouraged expression through movement. Participants were often asked to express a certain feeling or character and were also guided to make eye contact with others in the room. Participants were often asked to work in partners throughout the class.

While results from the DPQ did not show statistically significant changes, it is clear that participants involved in the ballet classes are gaining other important social and emotional benefits that are meaningful to them. Furthermore, throughout the course of the study, some participants began to meet with other

members of the class outside of the dance context. A group of dancing participants even started up their own choir. As such, participation in the ballet class has acted as a stimulus for participation and socialization in the community.

7.5 Chapter Summary

The present study found no significant changes across time or differences between groups in subscales of the Dance for Parkinson's questionnaire assessing changes to quality of life factors. Interviews, focus group discussions, and informal conversations found that the dancing participants are gaining other social and emotional benefits from the ballet classes. The ballet classes are providing an opportunity for people with Parkinson's to participate in the community and meet other people with a similar condition. The bonded community and feelings of support that have developed through the sessions may further stimulate participation and socialization outside of the dance context.

Qualitative data suggests that the participants enjoy the ballet sessions but the reasons why may be different depending on the person and what they value. Future research should try to assess quality of life variables through a variety of means, both quantitative and qualitative to gain a better picture about what is meaningful and important to the participants involved. Future research should continue to assess the relationships between factors affecting quality of life to better understand how changes to physical symptoms may impact upon activities of daily living and participation in society.

Chapter Eight

Considering Personal and Environmental Contextual Factors in Dance for Parkinson's Research

8.1 Personal and Environmental Contextual Factors

Chapters Four through to Seven have presented results from a wide range of assessments employed for this study. By separating the results into these four chapters the thesis aimed to evidence how the findings address all aspects of the ICF framework. Chapters Four and Five focused on changes in body functions, specifically gait variability as well as trunk coordination and range of motion. Chapter Six allowed for a discussion about changes in severity of motor and non-motor impairments in relation to ease of carrying out everyday activities. Chapter Seven explored factors that may influence participation in society while also assessing changes in perceived severity of symptoms and activities of daily living.

Arguments brought forth in Chapter Two demonstrated the need for a research framework that would encourage triangulation of information and subsequently lead to a better understanding of how dance is impacting this group physically, mentally, emotionally, and socially. The chapter argued for two different kinds of triangulation; the first demonstrated the need to discuss relationships between changes in impairments, activities of daily living and participation in order to draw stronger, more meaningful conclusions about the impact of dance on this group of people. Secondly, Chapters Two and Three argue for a mixed methods approach and a triangulation of information from quantitative and qualitative measures in order to better understand the potential changes taking place.

The previous four chapters have allowed for both kinds of triangulation with the use of quantitative and qualitative data to discuss the relationships between the various ICF domains. However, the chapters have not yet addressed personal and environmental contextual factors that may be influencing participant results. Previous chapters have not been able to achieve this kind of analysis due to the inability to consider such individual contextual factors when looking at statistical analysis of groups as a whole.

Chapter Two argued for an approach that does not neglect the person experiencing the dancing but rather considers their thoughts, feelings, and experiences. There is a need to understand that the results will be influenced by other factors including issues outside of the dance studio, such as family health and living conditions. Furthermore, the severity of Parkinson's symptoms can vary drastically on a day-to-day basis and the condition can be experienced in very different ways depending on the individual. As discussed previously, most research studies will try to account for variations amongst the group, usually by controlling for types and timings of medication as well as excluding people at certain stages of the condition. However, these control measures still do not account for how a participant's results may be affected by the loss of a loved one or how a participant's quality of life changes when they move into a new community or house. Although these issues appear to have no obvious connection to the dance classes, participants may experience the dancing differently as a result of these issues and may also present differently in testing situations.

Considering the points made above, it could be argued that the only way to account for the range of possible contextual factors playing a role in how dance can benefit the person with Parkinson's is to look at changes and experiences on a case-by-case basis. Furthermore, in the context of the present study where types and timings of medications and severity of condition were not restricted, case studies can provide additional insight into how the ballet-based dance classes may have influenced the lives of participants involved.

The purpose of the following chapter and the case studies described within it is to allow for a wider discussion about the relationships between all measurements employed in this study and across all ICF domains while also considering the personal and environmental contextual factors that may have impacted upon individual results. The aim of this chapter is not to necessarily support or refute the statistical results provided earlier, but rather to allow for consideration of contextual factors that may have influenced results and that could not be considered during the statistical analysis. This chapter argues that the only feasible way to account for these contextual factors is to look at the results on a case-by-case basis.

The participants described in the five case studies below were chosen based on the amount of quantitative and qualitative information that was gathered from each of them, as well as their specific contextual factors that would best highlight the necessity to consider such issues when reflecting upon the overall results. Interviews and focus group discussions were carried out with the dancing participants in an effort to better understand how the ballet classes were affecting

people physically, mentally, emotionally, and socially. As such, the following case studies will focus on five dancing participants.

The methods of assessment employed in this study have been categorized into the domains of the ICF framework that best represent the items being assessed. A summary outline of these domains and the relative assessments is presented in Table 5.1 below. For full descriptions and explanations as to why these assessments have been placed in their respective ICF domains, please refer to Chapters Four through to Seven in the thesis. Interviews and focus group discussions contained questions relating to all three ICF domains.

Table 5.1 ICF Domains and Relevant Assessments

ICF Domains and Relevant Assessments	
1	Body Function and Structure UPDRS Parts 1, 3, and 4 Gait Variability Trunk Coordination and Range of Motion During Gait Dance for Parkinson's Questionnaire Parts 1,3,5, and 7 Interviews and Focus Group Discussions
2	Activities of Daily Living UPDRS Part 2 Dance for Parkinson's Questionnaire Part 2 Activities-Specific Balance Confidence Scale Interviews and Focus Group Discussions
3	Participation Interviews and Focus Group Discussions Dance for Parkinson's Questionnaire Parts 4,6,8, and 9

As the previous four chapters have aimed to categorize the various assessments into the relevant ICF domains, the following case studies will also follow a

similar structure. Each case study will be divided into three subsections representing the three main ICF domains.

8.2 Case Study 1

8.2.1 Participant Background

Participant 121 began the study in September 2012 at the age of 69. She had been diagnosed for six years and taking medication for her Parkinson's prior to the onset of the study. Other than Parkinson's, participant 121 was also dealing with osteoporosis and arthritis during the study and discusses these conditions further within her one-to-one interview. The initial screening for the Mini-Mental State Examination (MMSE) demonstrated that this participant did not have signs of dementia at the onset of the study. Furthermore, her first UPDRS rating demonstrated an H&Y score (stage of Parkinson's) of two, which suggests her symptoms were presenting bilaterally without impairment to balance.

8.2.2 Body Function

Table 5.2 Case Study 1 (participant 121): Changes in Body Function

Assessment	Baseline	Short Term	Long Term
UPDRS Part 1	6	8	8
UPDRS Part 3	20	15	12
UPDRS Part 4	1	2	1
Step Variability	0.75	0.71	0.7
Stride Variability	0.77	0.79	0.87
Trunk Coordination (cross-correlation coefficients)	0.84	0.93	0.9
Trunk Coordination (percentage of gait cycle)	4.62	4.68	3.68
Pelvis ROM	13.64	15.3	19.32
Thoracic ROM	7.45	8.09	7.9
Perceived Present Health	1	X	2
Perceived Severity of Symptoms	4	X	5
Perceived Stage of Parkinson's	1	X	1
Perceived Mental Health	5	X	13

In relation to changes in body function, participant 121 demonstrated improvement in some areas and a slight decline in other items. Her scores increased with regards to her perception of Parkinson's symptoms and present health indicating these aspects were getting slightly worse across the long term, but not to the point where her perceived condition progressed (as evidenced in her perceived stage of Parkinson's result). However, it is interesting to note the results from the UPDRS part three (motor subscale) suggesting that she has improved quite dramatically from baseline. This measured result does not coincide with this participant's perception of health as measured through the DPQ across the study.

Participant 121 saw a slight decline towards more difficulties with non-motor aspects of daily living as assessed in the UPDRS part one. Supporting this result are scores from subscale five of the DPQ showing more difficulties with emotions such as feelings of depression and sadness.

Her trunk coordination during gait grew towards a more in-phase pattern across the duration of the study, demonstrating that the upper and lower torsos were moving together rather than in opposition. However, her range of motion during gait seemed to increase slightly in the thoracic area and quite strongly in the pelvis. This particular result and connection between trunk coordination and range of motion presents an interesting discussion in light of arguments brought forward in Chapter Five. This chapter looked at the potential role rigidity (or reduced range of motion), might play in trunk coordination and a tendency towards more in-phase patterns in Parkinsonian gait. Participant 121 presents an interesting case whereby range of motion appeared to increase when coordination patterns seemed to become more “rigid”. This finding could give reason to suggest that there are other factors involved in the lack of anti-phase coordination patterns during gait for this population. However, further investigation is needed to substantiate this conclusion.

In support of the findings above on improved range of motion, Participant 121 comments on how she feels improvement in her ability to twist and rotate around the spine:

121- *“The seated exercises are designed to increase the flexibility, which is a good thing because a lot of people don’t do much rotation.”*

Interviewer – *“It’s true, and do you feel that that’s helping you at all, that little bit of rotation that you do?”*

121- *“Yes, yes I do!”*

However, further along in the interview it becomes clear that this participant took part in contact improvisation workshops a few months earlier. Some of the exercises carried out in these improvisation workshops required participants to roll on the floor and practice getting up from the floor to a standing position. In the quotation below, Participant 121 comments on how she feels this material was extremely helpful in improving her rotation and ability to turn in bed and as such, she continues these exercises in her daily gym routine:

“We spent a lot of time rolling around and so I still do some of the rolling around exercises because we’ve got mats on the floor in the gym. So I find that’s quite useful. That’s helps turning over in bed I think.”

The ballet classes encouraged participants to increase stride length, which may have an effect on range of motion, particularly in the pelvis as the swinging leg extends further forward. Additionally, many seated exercises encouraged participants to twist in the torso and look at the wall behind them. However, it is possible that the exercises this participant carries out in the gym are the main

reason for the measured and perceived improvement in range of motion or axial rotation. Furthermore, information from health forms collected at each testing point demonstrate that this participant goes to the gym on a daily basis for at least 30 minutes, whereas she has been dancing only twice a week across the duration of the study, one class at English National Ballet and another class outside of the project.

Interviews and health forms provided additional information about other medical conditions. Before the onset of the study participant 121 was diagnosed with osteoporosis, a medical condition causing bones to become weak and brittle. When assessing body function and structure, whether done by the participant or therapist, it can be difficult to distinguish if symptoms are presenting due to another condition. It is possible that while the ballet classes may have helped to alleviate some Parkinson's symptoms, the osteoporosis was still affecting the participant and how she felt about her present health. Personal contextual factors such as the diagnosis of osteoporosis and the fact that this participant actively works on rotation in her daily gym routine should be taken into consideration when looking at her results.

Participant 121 did not report having any falls across the duration of the study, though she mentions in her interview that she did suffer a few falls prior to the start of the project. With regards to dynamic stability as measured via gait variability her results show an improvement in stride consistency, although her step patterns became slightly more variable. This finding of increased step variability with decreased stride variability is not uncommon and shows that

although neighbouring steps may not be exactly the same, the stride patterns (two steps one after the other) are growing more consistent. Some individuals spend longer on one foot than the other but are consistent with that pattern when walking across a particular distance. This improved consistency may indicate improved dynamic stability during walking which is then reflected in the lack of falls experienced across the duration of the study.

8.2.3 *Everyday Activities*

Table 5.3 Case Study 1 (participant 121): Changes in Experiences of Daily Activities

Assessment	Baseline	Short Term	Long Term
UPDRS Part 2	8	5	5
Balance Confidence	79.38%	63.13%	71.25%
Activities of Daily Living Feeling at Wors	3	X	3

With regards to activities of daily living, participant 121 demonstrated a slight improvement across the duration of the project in UPDRS part two scores. When asked about activities of daily living when feeling at her worst (as was seen in the DPQ), she reported feeling no difference across the 12 months of study.

The slight improvement noted in UPDRS part two scores coincides with the improvement seen in her UPDRS part three scores. It could be that improvements in motor impairments were helping this participant to carry out daily tasks and activities.

However, this participant does feel a general lack of energy as a result of her Parkinson's. She discusses the difficulty in ensuring that she has a balance of daily activity with an appropriate amount of rest so that she does not feel too exhausted and fatigued:

"I find that I don't have much energy. And I realise as you get older you lose energy. But I think that the Parkinson's has basically accelerated ageing, quite frankly.... it means that you can't plan to do too much in one day because you just end up feeling very tired...and when you get tired you don't feel like going out and socialising. On the other hand you can have too little to do in a day which is depressing or you can have too much to do which is tiring. And it's almost impossible to get just the right amount in a day so that you're not too tired out or you're not too depressed at the end of the day...it's tricky."

Fatigue and problems with daytime sleepiness are assessed in UPDRS part one, where this particular participant saw a slight trend towards increased difficulties across the duration of the project.

Although this participant did not report any falls across the duration of the project, she did see a slight decline across the short and long term with respect to balance confidence. In the interview she makes note of how her diagnosis of osteoporosis affects her balance confidence, possibly even more so than instability stemming from her Parkinson's:

“I used to like going out walking, but since I got the, well it’s mainly the osteoporosis. I am a bit more scared of falling because the osteoporosis people have told me that I can’t cycle because if I fell off my bike again I’d break something. So the osteoporosis limits your horizons as well.”

“The combination of the lack of energy and the not wanting to fall over means that I don’t do quite a few of the things that I used to do, bicycling and walking that sort of stuff.”

Although this participant rated a slight improvement with ease of daily activities, it appears that she chooses to not carry out certain activities that could potentially put her at risk of falling. However, the osteoporosis plays a large role in this fear of falling and the subsequent avoidance of certain activities.

8.2.4 Aspects of Quality of Life & Participation

Table 5.4 Case Study 1 (participant 121): Changes in Aspects of Quality of Life and Participation

Assessment	Baseline	Short Term	Long Term
Sense of Freedom	4	X	4
Certainty about Future Life	41	X	48
Interference of Illness on Life	22	X	7
Perceived Quality of Life	1	X	2

When asked about how free she feels to do the things that she would like to do, Participant 121 did not see any change across the duration of the study. Initial one-to-one interviews show that this participant, while still being a fairly active

person, felt a certain level of stress and anxiety when doing something different or meeting new people. However, the quotation below demonstrates that this does not stop her from participating because she understands the benefits of taking part in new things:

“The other thing I find is that the things I normally do, I am quite happy to do but if something is new and different then I can be a little bit more inclined to think ‘what if this happens or what if that happens,’ and it’s just something out of the norm. So I try to do things that I don’t always do just to prevent, try to prevent myself from getting into a rut.”

Scores from subscale six of the DPQ show that this participant has grown more certain and confident about maintaining a positive future life inclusive of making new friends and continuing to enjoy learning new things. As such, participation in the ballet-based classes may be having a positive affect on how this participant feels about future participation in the community.

Participant 121 saw a strong improvement in subscale eight of the DPQ that looked at interference of Parkinson’s on aspects of life such as personal relationships, self-efficacy, and sense of independence. While this participant may still perceive that her physical and psychological symptoms are progressing and may also avoid activities that have a higher fall risk, she has become better able to cope with these symptoms and maintain important aspects of her life across the study.

With her Parkinson's interfering less with important life factors such as personal relationships and self-efficacy, and ignoring other conditions such as her osteoporosis which may influence her, one could argue that she is more likely to continue being an active participant in society in the future.

Throughout the course of her study, participant 121 maintained an attendance level above 80%. The strong adherence and attendance to the ballet-based sessions also suggests that this participant feels she is gaining things that are important to her quality of life. Interview and focus group discussions suggest that she feels the social interaction is an important aspect of the classes:

“Well there's also the emotional side of it. I don't know if other people are like me but I find that if I have things planned ahead for me to go to, this is a good thing, and particularly things that I enjoy doing.”

Furthermore, this participant feels that the music is an important and motivating part of the dancing experience and may be cause for improved fluency during gait. In the following quote she notes how music is influencing her own movement:

“I'm no dancer but I do definitely find that I respond to the music.”

It appears that participant 121 is gaining other social and emotional benefit from the classes and values the positive impact that music has on her movement.

8.2.5 *Summary*

For participant 121, there were some differences between her perception of health and the results from biomechanical assessments and administered rating scales. However some interesting connections were made when triangulating the results from various measures. For instance, as both her UPDRS part two and part three scores improved, it was suggested that improvement in her motor impairments might be helping this participant to carry out everyday activities with more ease and efficiency. The fatigue and lack of energy that she discussed in detail during her interview resonates with her results from part one of the UPDRS that showed a slight decline in score. Furthermore, the connection between her trunk range of motion and coordination results suggests that a lack of range in the upper and lower trunk are not necessarily the cause for the more in-phase gait pattern in this individual.

There were two key contextual factors that were discussed within this case study. Firstly, this participant has been diagnosed with osteoporosis and arthritis and she discussed in her interviews how this also affects her movement and everyday activities. Secondly, participant 121 attended the gym daily and worked specifically on aspects of trunk rotation that were also being assessed in this study. These personal contextual factors could help to explain some of the findings for this participant, however these issues could not be addressed in previous chapters when looking at the dancing group as a whole.

The fact that participant 121 maintained a high attendance level across the study suggests that she was motivated to attend and participate in the ballet classes. Interview data suggests that she enjoyed the social interaction, social support and musical accompaniment and that these may be key motivators for this individual to participate in future activities.

8.3 Case Study 2

8.3.1 Participant Background

Participant 115 began the study in September 2012. At the onset of the study she was 66 years of age and had been diagnosed with Parkinson's for six years. She did not report any other medical conditions and was taking medications for her Parkinson's across the duration of the study. Her initial screening demonstrated that she did not have any signs of dementia as assessed via the MMSE and she had an H&Y score of two as assessed via the UDPRS scale.

8.3.2 Body Function

Table 5.5 Case Study 2 (participant 115): Changes in Body Function

Assessment	Baseline	Short Term	Long Term
UPDRS Part 1	5	6	5
UPDRS Part 3	22	12	14
UPDRS Part 4	0	1	0
Step Variability	0.93	0.92	0.94
Stride Variability	0.94	0.94	0.96
Trunk Coordination (cross-correlation coefficients)	0.64	0.8	0.77
Trunk Coordination (percentage of gait cycle)	3.52	6.33	8.16
Pelvis ROM	4.43	7.61	5.61
Thoracic ROM	8.22	5.79	6.02
Perceived Present Health	4	X	4
Perceived Severity of Symptoms	11	X	11
Perceived Stage of Parkinson's	1	X	3
Perceived Mental Health	8	X	8

In relation to changes in body function, participant 115 saw a change for the better in a variety of areas. While results from the DPQ show no change with regards to perceived severity of symptoms when feeling at her worst, her UPDRS part three (motor subscale) scores suggest that she has seen a clinically meaningful improvement in both the short and long term. The above results are particularly interesting when comparing them to her ratings of her stage of Parkinson's. It appears that while this participant has rated no change in the severity of her Parkinson's symptoms (when feeling at her worst), she has rated that her stage of Parkinson's has progressed with respect to the Hoehn and Yahr scale. Within the context of this scale, the shift in progression meant that at baseline, the participant perceived she was only experiencing symptoms on one

side of the body whereas by the end of the study she progressed to symptoms on both sides with some additional postural instability reported. Thus, in one of the DPQ subscales she rated that her Parkinson's had progressed and in another DPQ subscale it appears she rated no change in severity of symptoms. Both of these results are different to the results of the motor subscale within the UPDRS, which show clinically meaningful improvement in motor symptoms.

Although this participant felt her condition had possibly progressed across the 12 months, her step and stride variability results show a slight improvement towards a more consistent gait rhythm. However, her results at baseline demonstrated a fairly consistent rhythm at the onset of the study indicating this participant was already walking in a fairly consistent, rhythmic manner. Nevertheless, this more consistent pattern may indicate improved dynamic stability during gait. This participant makes note of an increase in intensity during a particular dancing term that may have been helping to improve aspects of gait rhythm:

“It would be good for us, if it could be done safely, gradually and safely because, I mean, I’m very conscious of the fact that I don’t do that sort of exercise. I never really get to the point of being out of breath because you just don’t have the juice in your legs to walk fast, but on the other hand, having said that, thinking back to Rite of Spring, there were minutes and minutes and minutes of stamping...clapping and stamps. So we can when we build up to it.”

However, it is important to note that at baseline, this participant reported recently suffering a fall that injured her right knee. Though no serious injury had occurred, the right knee remained swollen and painful for weeks. It is possible that this personal contextual factor may have influenced how this participant performed at baseline and as her rehabilitation progressed, her performance improved.

This participant takes part in another weekly dance class at a different location and has done since the start of the project. However, she does not take part in any other regular exercise regimes other than walking and Pilates workshops once a month at her local Parkinson's support group. As such, it appears that the dancing may be helping to maintain and in some instances improve aspects of body function for this participant.

Participant 115 demonstrated increased range of motion in the pelvis in both the short and long term but saw a trend towards decreased range of motion in the thoracic area. The increased range of motion in the pelvis could be due to the amount of time spent walking in the ballet-based sessions with verbal cues from instructors encouraging participants to increase stride length. Throughout the course of the project participant 115 had difficulties with posture, and in particular a tendency to stoop in the thoracic spine and lean to the side. Instructors in the dance class often made an effort to correct this participant's posture on a regular basis when they would see her falling into habitual resting positions. However, this postural tendency may be affecting range of motion in the thoracic region and may also be affecting coordination in the trunk. Results

show that the trunk and pelvis were moving in a more in-phase pattern across the duration of the study.

With regards to aspects of perceived mental and emotional health, participant 115 saw no change as evidenced in subscale five of the DPQ. Supporting this finding are results from part one of the UPDRS looking at non-motor aspects of daily life experiences. Again, this participant did not show any change across the duration of the study. As Parkinson's is a degenerative condition that can affect both physical and mental functioning, a result that shows no change may be considered a positive finding.

8.3.3 *Everyday Activities*

Table 5.6 Case Study 2 (participant 115): Changes in Experiences of Daily Activities

Assessment	Baseline	Short Term	Long Term
UPDRS Part 2	5	7	6
Balance Confidence	85.00%	85.00%	82.00%
Activities of Daily Living Feeling at Worst	1	X	2

In relation to activities of daily living, participant 115 reported a slight shift towards having more difficulties with everyday tasks, both on average and when feeling at her worst. This finding presents an interesting discussion in light of changes seen in the motor subscale. While this participant demonstrated improvement with regards to motor impairments, these improvements did not

positively impact her perceptions of difficulties with everyday motor tasks. McGill, Houston, and Lee (2014) argue that by looking at changes from different perspectives using the ICF framework, researchers can draw stronger, more meaningful conclusions about the potential impact dance is having on people with Parkinson's. While several articles in the field have shown that dance can help improve motor impairments such as balance and gait disturbances, few studies look at how these changes impact upon the participants' daily lives outside of the studio. If improved motor impairments are not aiding activities of daily living, questions may arise as to how meaningful the measured motor changes are for the participants.

While this participant saw a very slight decline in balance confidence, she did not report any change in fall rates across the duration of the study. As mentioned previously this participant suffered one fall at baseline and reported one fall in the three months prior to the final testing. However, she notes that the particular situation meant that "anyone would have fallen" and that this was not due to instability from her Parkinson's. Nevertheless, her confidence scores remain quite high in relation to the rating scale guidelines. As discussed in Chapter Four, Myers et al. (1998) suggests that an ABC total score above 80% is indicative of a high level of physical functioning. Participant 115 remained above 80% across the duration of the study. Although the slight decrease in balance confidence does not seem to correspond with the slight improvement in gait variability patterns, it appears this participant is still feeling fairly confident that she can remain stable in many day-to-day tasks.

8.3.4 Aspects of Quality of Life & Participation

Table 5.7 Case Study 2 (participant 115): Changes in Aspects of Quality of Life and Participation

Assessment	Baseline	Short Term	Long Term
Sense of Freedom	3	X	3
Certainty about Future Life	39	X	47
Interference of Illness on Life	35	X	21
Perceived Quality of Life	3	X	3

This participant was a fairly active and independent individual at the onset of the study and reports that she is busy most days with various groups and Parkinson's-related activities:

“Having Parkinson's can be quite time consuming. I mean just in terms of belonging to groups and writing newsletters and all of those sorts of things. And they all take time.”

Initial one-to-one interviews demonstrated how this participant felt that the Parkinson's was not keeping her from doing the things that she wanted to do:

Interviewer – “And that's really what this part of the interview is about is whether you are still feeling active and as though you can participate in things.”

115– “Oh absolutely!”

Interviewer – “Yes well it is really what this section was about. Is the Parkinson’s stopping you from doing the things in society that you would like to do and it doesn’t sound like it is.”

115 – “No I don’t think it is.”

When asked in the DPQ about how free she feels to do the things that she would like to do, Participant 115 did not see any change across the duration of the study. This result coincides with discussions from the one-to-one interview that demonstrate her sense of independence and ability to continue carrying out normal everyday tasks:

“I’ve never had any assistance. The only thing I don’t do that I used to is that when we go to the supermarket, we go together because P drives and I gave up driving. I used to do the supermarket shopping on my own, I mean I don’t like it. He would do it on his own but I do most of the cooking because I like doing most of the cooking and if you do that you kind of want to go buy the stuff yourself. Apart from that I don’t think there is anything else that I need help with.”

In relation to aspects of mental and emotional health as discussed above, it could be that her continued sense of independence and willingness to take part in other social activities may be helping her to maintain mental health and a good quality of life.

Scores from subscale six of the DPQ show that this participant has grown more certain about maintaining aspects of a positive future life including having hope for the future, having fun, and making new friends. This participant also saw a strong improvement in subscale eight that looked at interference of Parkinson's on aspects of life. With her Parkinson's interfering less with such important life factors as personal relationships and self-efficacy, she may be more likely to participate in other activities and social engagements in the future.

Throughout the course of her study, participant 115 maintained an attendance level above 90%. Interview and focus group discussions suggest that she feels the social interaction is an important aspect of the dancing experience. When talking about the other dance class that she attends, participant 115 says:

“They picked up that we didn’t really want the class split because an important part is the feeling within the group that we were, you know like the tribe that we had in the Rite of Spring (ENB class), you know I think that’s kind of what we feel.”

Participant 115 also feels that the music is motivating and encourages people, including herself, to move and be active:

Interviewer- “why would you encourage dance as opposed to other exercise regimes?”

115 – “Because people will do it because they enjoy it more! It’s the music basically.”

Interviewer – “I love that. It’s the music! It’s true, moving to music is different than a lot of other things that you are doing.”

115 – “Absolutely, so it will persist. I mean you put the music on and you’re dancing and you can’t help it! It’s undoubtedly the music. I mean for me it is, certainly”

In focus group discussions participant 115 discusses how she values the focus of the classes being on the art form itself rather than on Parkinson’s. She says that for her it is not about “this is going to be good for me.” As such, it seems this participant is not as concerned about how the exercises or specific movements are going to benefit her or relieve Parkinson’s symptoms, rather she values the other aspects of the class including the social interaction and the music.

Across the duration of the study, this participant demonstrated an increase in hours spent walking outside of her house. It appears that this participant has grown more active across the duration of the study and continues to take part in activities within her local Parkinson’s support group and both dance classes. The improvements seen within her UPDRS motor subscale scores may be a result of this increased activity level and her continued engagement with dancing.

8.3.5 Summary

Participant 115, in a similar fashion to participant 121 described in Case Study 1, demonstrated differences between scales that assessed her perception of health and scales that were administered to measure symptom severity and progression. For instance, her UDPRS motor subscale scores indicate clinically meaningful improvement in the short and long term however her DPQ results show a worsening in perceived severity of symptoms. The comparison of scales within the UPDRS shows that while her motor impairments may have improved, these improvements were not carrying over to her perceived level of difficulty with everyday tasks and activities.

With regards to personal contextual factors, some key points were made throughout this case study. For instance, this participant suffered a fall, which left her with pain and discomfort in the lower limbs just before her baseline measurement. Thus, improvement in motor tasks, particularly the gait measurements may have been influenced by the fact that this participant was experiencing pain at baseline. However, it was not possible to account for this in the previous statistical analysis.

This participant did not take part in any other regular physical activity other than walking for the length of the study, however she did take part in another dance class on a weekly basis. As the majority of participants in this research study only took part in ballet once per week, it is important to consider this contextual

factor, particularly when looking at the clinically meaningful improvements in her UPDRS motor subscale scores.

Observations in class and film footage evidenced the difficulties this particular participant had with posture and a tendency to lean sideways in the thoracic spine. An understanding of her difficulties with posture is important when considering the decline in her thoracic range of motion during gait.

Qualitative data from interviews noted how this participant does not attend the classes thinking solely about how the movement will be good for her. Rather she is motivated by other elements of the ENB programme including the social support, the music, and the cultural and educational nature of the sessions.

8.4 Case Study 3

8.4.1 Participant Background

Participant 116 began the study in September 2012 at the age of 70. He had been diagnosed with Parkinson's for three years and did not report any other medical conditions at the onset of the study. However, upon completion of the research this participant was diagnosed with cancer and underwent chemotherapy treatment. An initial screening demonstrated that this participant did not show any signs of dementia at the start of the study as assessed through the MMSE and had an H&Y score of three, outlining that he experienced symptoms on both sides of the body and had some difficulties with postural stability.

8.4.2 Body Function

Table 5.8 Case Study 3 (participant 116): Changes in Body Function

Assessment	Baseline	Short Term	Long Term
UPDRS Part 1	9	11	11
UPDRS Part 3	36	29	21
UPDRS Part 4	1	1	0
Step Variability	0.84	0.76	0.7
Stride Variability	0.82	0.82	0.83
Trunk Coordination (cross-correlation coefficients)	0.88	0.92	0.74
Trunk Coordination (percentage of gait cycle)	3.75	2.78	6.62
Pelvis ROM	6.47	6.44	6.99
Thoracic ROM	6.31	6.38	3.95
Perceived Present Health	3	X	4
Perceived Severity of Symptoms	13	X	15
Perceived Stage of Parkinson's	3	X	3
Perceived Mental Health	5	X	6

In relation to changes in body function, results from the DPQ show that participant 116 reported his Parkinson's symptoms as slightly more severe by the end of the study. Furthermore, his results show a very slight decline in perceived level of present health. However, the reported change was quite small on both accounts. Results from part three of the UDPRS (motor subscale) show a clinically meaningful improvement in the short and long term with regards to motor impairments. It is important to note however that when asked about severity of symptoms in the DPQ, the participant is asked to rate how severe these symptoms are at their worst. In any case, it appears that the change in his

ratings of perceived symptom severity were quite different to changes seen in the UDPRS scale.

With regards to non-motor aspects of daily life experiences as assessed in the UPDRS, participant 116 reported slightly more difficulties with these issues by the end of the study. This result coincides with changes to perceived aspects of emotional health as rated in the DPQ. Results in this subscale of the questionnaire show a very slight decline towards a more dysphoric mood. However, again this change is quite small (increase of 1 point).

The following quotation was also brought forth in Chapter Seven and reiterates what this participant feels with regards to the potential physical and mental impact of dancing:

“Yes I think there are two things, one is physical and the other is social. Physically, as I said before it is hard to distinguish the effect of dance but I think it does help and quite often it is the non-physical things that are helping as much as anything”

Later in the interview the idea of non-physical benefit came up again:

Interviewer- “Is there anything else, before we move on, that you think dance is giving you that you feel other activities would or wouldn’t?”

116- *“I do sometimes think about the memory, I think sometimes the ballet exercises are very complicated. It can be a little frustrating actually.”*

Although this participant feels that the dancing is probably doing him some good physically, it is difficult for him to verbalize what exactly may be changing for the better. However, he makes note that non-physical elements are helping and possibly more so than the physical. That said he feels that at times remembering the sequences can be quite difficult to the point of frustration and thus this may not always be beneficial for mental and emotional wellbeing. Although this participant did not see any improvements in non-motor aspects of daily life experiences as measured in the UPDRS part one, his comments in interviews suggest that he feels he is gaining psychological and social benefit. Later in the one-to-one interview this participant makes note of balance difficulties that he experiences:

“Certainly walking is a bit difficult anyway so I tend to not do that much walking. Cycling I do have one problem which is sense of balance, so I tend to wander around as well... Same as running really there is the question of balance.”

However, these stability problems are being discussed in the context of specific activities and not on a general day-to-day basis.

Participant 116 reported one fall in the previous three months before baseline testing but after that did not report any falls for the duration of the study. With regards to dynamic stability as measured via gait variability his results show a very slight (1%) improvement in stride consistency, although his step patterns became more variable.

With regards to trunk coordination and range of motion during gait, participant 116 demonstrated a more in-phase movement pattern. However, the movements of the trunk and pelvis became less correlated and the percentage of gait cycle increased across the duration of the study. This could indicate a move towards a more anti-phase pattern but further investigation would be needed. Participant 116 also demonstrated improved range of motion in the pelvis however thoracic range of motion appeared to decline and become more rigid across the duration of the study. These range of motion changes support the discussions above with regards to the decrease in correlation of trunk movements. Perhaps it is the improved pelvic range of motion that is instigating a move towards a more anti-phase pattern.

With regards to physical improvements, it is important to note that this participant takes part in the initial warm up section of a Tai Chi class on most mornings throughout the week. Furthermore, he feels that he is gaining some physical benefit from these sessions as well:

“I think it helps maintain the muscles but I think the main thing is simply bending. I have no back problems and I think that is partly because every morning I do these bending exercises.”

As participant 116 is participating in this Tai Chi warm-up every morning, yet only participates in ballet once a week, it is difficult to say how much the ballet is affecting physical change.

8.4.3 Everyday Activities

Table 5.9 Case Study 3 (participant 116): Changes in Experiences of Daily Activities

Assessment	Baseline	Short Term	Long Term
UPDRS Part 2	20	21	18
Balance Confidence	63.75%	67.50%	70.63%
Activities of Daily Living Feeling at Wors	11	X	13

When looking at changes to motor aspects of daily life experiences on average, participant 116 saw a slight improvement in the long term. However, when asked about these experiences when feeling at his worst, this participant saw slightly more difficulties with activities of daily living. As the questions in subscale two of the DPQ are based upon questions asked within the UPDRS scale, the main difference appears to be how the participant feels on average versus feeling at their worst. However, it is important to note discussions in Chapter Six about the UPDRS part two subscale and how it includes items that are not related to

functional movements, such as changes to tremor, excess saliva, and drooling. The activities of daily living subscale seen within the DPQ only include functional activities and not unconscious body functions. This may also be the reason for the differing results.

The slight improvement seen in the UPDRS part two scale coincides with an improvement to motor impairments seen in the UPDRS part three scores. In this case it may be that the improvements to motor impairments are having a positive impact on everyday activities and tasks for this participant.

Participant 116 saw improvement in balance confidence across the duration of the study. As discussed above, while this participant brought forth concerns of balance in particular situations or activities, this scale asks about how confident the participant is that they can maintain stability in a variety of everyday tasks. The improvement corresponds to an improvement seen in the UPDRS part two subscale looking at ease of carrying out everyday activities and also relates to the improvements seen in his UPDRS motor subscale scores. Again, it could be that these physical improvements are helping this participant to feel more confident about these everyday tasks that require stability.

8.4.4 Aspects of Quality of Life Participation

Table 5.10 Case Study 3 (participant 116): Changes in Aspects of Quality of Life and Participation

Assessment	Baseline	Short Term	Long Term
Sense of Freedom	4	X	5
Certainty about Future Life	42	X	42
Interference of Illness on Life	28	X	26
Perceived Quality of Life	3	X	4

Initial interviews at the onset of the study suggested that this participant felt quite independent and was able to participate in activities that he enjoyed:

Interviewer—“... do you find you have any trouble doing these things, stability if that’s an issue, or are you pretty comfortable going out there and doing these activities on your own?”

116— “I am entirely comfortable. I still go out a fair amount and one thing that’s always been with me is I have always been willing to get involved in societies and things like that so I am a member of about 3 or 4 different societies. It naturally causes meetings and those sorts of things.”

When asked how free or restricted he felt in doing the things that he wants to do, this participant rated feeling slightly more restricted as the study progressed. Furthermore, his rating of quality of life slightly worsened across the time of the study. However, his certainty about maintaining a positive life in the future

inclusive of making new friends and continuing to enjoy learning new things remained the same across the study. Furthermore, his ratings on the interference of illness scale improved showing that his Parkinson's is interfering less on aspects of life such as personal relationships, self-efficacy, and sense of independence. This mixture of results presents an interesting case whereby aspects of quality of life, which we may view as being connected, are actually showing differing results and changes across time. While participant 116 rated feeling more restricted and having a slightly reduced quality of life, he also rated that his Parkinson's was interfering less with important life aspects. It could be that other personal contextual factors or conditions are having an impact on this participant's sense of freedom and quality of life. After the study finished, participant 116 was diagnosed with cancer and had to undergo chemotherapy treatment. It is possible that he was not feeling well near the end of the study due to his cancer, however this cannot be confirmed.

Throughout the study, participant 116 maintained an attendance level above 90%. The strong adherence to the ballet classes suggests that this participant feels he is gaining things that are important to him such as social inclusion. Furthermore, this participant talks about how his participation in these classes has been a useful point of discussion in conversations outside of the dance context:

“Yes that’s part of the point that because I am doing ballet I have a handy topic of conversation. People are really intrigued by it so that again is kind of a social boost, a boost to mental health.”

When asked about anything else that the dance classes are providing that other physical activities may not, this participant states:

“It is cultural as well!”

It appears this participant is gaining a certain amount of social benefit and values the activity for what it is, an art form as well as a physical activity.

8.4.5 Summary

Participant 116 also saw differing results with regards to his perception of changes in severity of symptoms and present health and some of the other quantitative measures assessing these variables. While he demonstrated a strong improvement in the motor subscale of the UPDRS, he saw slight declines in his perception of symptoms and health when feeling at his worst in the DPQ results. Participant 116 found it difficult to say for certain if anything was changing for the better physically as a result of the ballet classes but he felt that the ballet may be providing more non-physical benefits. These comments from the one-to-one interviews are interesting given that this participant saw a decline in his ratings of mood within the DPQ as well as non-motor aspects of daily life experiences in part two of the UPDRS.

Although this participant did not see any strong changes in dynamic stability, his coordination results suggest that there might be a move towards a more anti-phase pattern. It could be that the improved pelvic range is helping him to move

towards a more anti-phase pattern but the lack of change in the thoracic range is not helping his stability during gait.

There were two personal contextual factors discussed in this case study that should be considered when reflecting on this participant's results. Firstly, this participant took part in daily Tai Chi warm up classes each morning. As these classes were carried out daily and the ballet classes were only carried out once a week, it is difficult to understand how each activity affected this participant physically. Secondly, after the study finished participant 116 was diagnosed with cancer. It is unknown if difficulties with his health in relation to the cancer were affecting this participant prior the completion of the study. This participant rated that his Parkinson's was interfering less with important life aspects by the end of the study but he still demonstrated declines in other quality of life aspects. It could be that other health issues were impacting upon some of these quality of life factors.

8.5 Case Study 4

8.5.1 Participant Background

Participant 119 began the study in September 2012 at the age of 75. She had been diagnosed with Parkinson's for five years prior to the onset of the study and was taking medication for her Parkinson's. With regards to other medical conditions this participant noted that she was also dealing with issues around cholesterol and blood pressure. She also recorded issues with fibrosis of the lung

and needing to see a cardiologist on a regular basis about her heart, for which she was given an additional exercise programme to work on independently for one hour per week. At the onset of the study this participant did not show any signs of dementia and had an H&Y score of two, indicating symptoms presenting on both sides of the body without any balance impairment.

8.5.2 *Body Function*

Table 5.11 Case Study 4 (participant 119): Changes in Body Function

Assessment	Baseline	Short Term	Long Term
UPDRS Part 1	10	8	9
UPDRS Part 3	13	13	17
UPDRS Part 4	0	0	0
Step Variability	0.9	0.84	0.78
Stride Variability	0.91	0.91	0.82
Trunk Coordination (cross-correlation coefficients)	0.95	0.89	0.79
Trunk Coordination (percentage of gait cycle)	1.5	4.24	4.58
Pelvis ROM	7.05	7.34	7.9
Thoracic ROM	7.78	7.68	7.98
Perceived Present Health	3	X	3
Perceived Severity of Symptoms	7	X	6
Perceived Stage of Parkinson's	1	X	1
Perceived Mental Health	5	X	5

In relation to changes in body function, participant 119 reported a very slight improvement across the study with respect to perceived severity of her Parkinson's symptoms when feeling at her worst. However, she did not see any change in perceived sense of health or her stage of Parkinson's.

Initial interviews support the findings above. The following quotation was also brought forward in Chapter Seven and demonstrates how this participant responded when asked about any physical or mental benefit she was experiencing as a result of the dancing:

“Well I suppose slight improvement, slight. You see I had lost my confidence when I got Parkinson’s. Afraid to cross over the street you know and even afraid driving, won’t go on the motorway, I stay around the spaces that I know. But so, I know that it helps me, as I say, I am much better in some ways... I think my balance is slight... slightly better. Can’t say.”

However, her UPDRS part three (motor subscale) scores seem to suggest a slight decline or worsening of motor impairments across the study. Correspondingly her gait patterns became more variable and less stable across the duration of the study, indicating more problems with dynamic stability during walking. However, she did not report any falls across the duration of her study. Comments above about her uncertainty with regards to changes in balance seem to reflect the lack of positive change in the gait variability result.

In the case of participant 119, attendance may be an important contextual factor to consider. This participant’s attendance was far more sporadic than most participants. Across the 12 months each dancer experienced 3 terms of ballet-based classes. In her first term participant 119 attended 63.64% of the offered classes, in the second term only 18.18%, and in the final term 55.54%. This

participant often goes away on holidays abroad for extended periods of time and this is why attendance is sometimes low. Furthermore, she travels to classes by bus and as such, bus strikes or events in the city mean that it can be difficult for her to attend class at times.

Additionally, this participant is dealing with other health issues including high blood pressure, cholesterol problems, fibrosis in the lung, and issues with her cardiorespiratory system. Furthermore, near the end of the study this participant made a change to her medication and also began to report dizzy/faint spells. These personal and environmental factors are important to consider in relation to the results. It could be that her lack of attendance, particularly in the second term, influenced how much dance could impact upon her physical health. Furthermore, other health issues or side effects from medications may be playing a role in how she perceived her state of health.

The pelvis and thorax were moving in a more in-phase pattern during the study. However, her coordination patterns moved slightly away from an in-phase pattern across the study. This along with the increase in percentage of gait cycle may indicate a move towards a more anti-phase pattern. However, further investigation would be needed to substantiate these conclusions. Participant 119 also saw an improved range of motion in both the lower and upper trunk. As discussed in Chapter Five it could be that this improved range of motion and ability to rotate further around the central axis may play a role in moving towards a more anti-phase coordination pattern in the trunk.

With regards to non-motor aspects of daily life experiences as measured through part two of the UPDRS, participant 119 saw a slight improvement. Furthermore, with regards to emotional health as measured via subscale five in the DPQ, this participant did not experience any change across the duration of the study. While these questions focus on how the individual has felt on average over the past week, participant 119 shares her thoughts about how the dance classes make her feel:

“... It makes me happy when I’m there. Happy and mentally good! And that’s to do, apart from the dancing which is very interesting, it’s the personalities of all those who are there.”

“And that means a lot. Go to some place where you are genuinely wanted and the fact that you are disabled it doesn’t mean a darn thing.”

“You’re alive!”

Although participant 119 did not show any change with regards to emotional health as measured via subscale five in the DPQ, it appears that the dancing is making her feel happy and supported.

8.5.3 *Everyday Activities*

Table 5.12 Case Study 4 (participant 119): Changes in Experiences of Daily Activities

Assessment	Baseline	Short Term	Long Term
UPDRS Part 2	4	3	2
Balance Confidence	53.13%	60.44%	61.88%
Activities of Daily Living Feeling at Wors	2	X	3

Participant 119 saw a trend towards improvement with respect to motor aspects of daily life experiences as measured using part two of the UPDRS with a low score of two points seen at the final testing. However, when asked about activities of daily living when feeling at her worst, she rated slightly more difficulties with these everyday tasks and activities. As discussed previously, the questions in subscale two of the DPQ are based upon questions asked within the UPDRS scale and as such the main difference appears to be how the participant feels on average versus at their worst. The results may be due to the fact that part two of the UPDRS includes items that are not related to functional movements.

Participant 119 saw a strong improvement in balance confidence scores in the short and long term. This finding is interesting given the lack of positive change in the gait variability measurement and the uncertainty about change to balance reported in interviews. However, these interviews were held earlier on in this participant's study and thus, the changes to balance confidence might have occurred after that initial discussion. Furthermore, her relatively low balance

confidence scores still place her in the category of low physical functioning and at a higher risk of falls (Myers et al., 1998; Lajoie and Gallagher, 2004).

8.5.4 *Aspects of Quality of Life & Participation*

Table 5.13 Case Study 4 (participant 119): Changes in Aspects of Quality of Life and Participation

Assessment	Baseline	Short Term	Long Term
Sense of Freedom	6	X	4
Certainty about Future Life	37	X	42
Interference of Illness on Life	28	X	18
Perceived Quality of Life	2	X	2

Initial one-to-one interviews with this participant evidence how she did not feel that her Parkinson's was getting in the way or stopping her from participating in the things that she wanted to do:

“Interviewer - Do you feel that you are still able to take part in these activities or do you feel that your Parkinson's is somehow stopping you?”

“119 – no, not yet and I wouldn't allow that. Mentally I wouldn't allow that.”

When asked how free or restricted she felt in doing the things that she wanted to do, participant 119 reported feeling more free by the end of the study. Furthermore, this participant grew more certain about maintaining positive

aspects of her life in the future. As such, participation in the ballet classes may have a positive affect on how this participant feels about future participation in the community. This participant also found that her Parkinson's was interfering less with important quality of life factors such as maintaining personal relationships and a sense of independence.

With respect to the ballet classes, although the participant sometimes had extenuating circumstances where she could not attend at certain times of year, it appears that she values the classes and the social and emotional benefits that she gains from it.

"You have to be with people!" (to be motivated to exercise)

"Well it's the dance, music, personalities, and just the atmosphere!"

She also feels the music plays an important role in why people are motivated to dance and what the music does for her.

"... How can I put it, I am not a shaker or a mover in any way, but rhythm, when it starts you want to go don't you! And you feel much better."

"I think so, I think it's the music (that motivates people)."

8.5.5 Summary

In a similar way to the participants described in case studies one to three, participant 119 demonstrated differing results between her perceived severity of symptoms and some of the other quantitative measures assessing those symptoms. However, this participant, unlike those discussed above, saw a slight improvement in the perception of her symptoms whereas measures of motor impairments via the UPDRS part three and measures of gait variability did not show positive improvement. When asked in the one-to-one interview participant 119 perceived a slight improvement with regards to her physical functioning however she was not able to pin point exactly what had changed for the better. It could be that this participant was trying to bring forward something positive in the interview context but we cannot know this for certain. That said she did see a slight improvement towards a more anti-phase coordination pattern during gait. However, it is suggested that further investigation be carried out to substantiate these conclusions.

When talking to participant 119 it was clear that she was keen to discuss how she felt the dance classes made her feel happy and that this was due to a mixture of the physical activity as well as the personalities of all those involved. Although no large changes were seen in non-motor aspects of daily life experiences as assessed in the UPDRS and DPQ, the questions within these scales focused more on general feelings across an average week rather than within the dance context. Furthermore, this participant saw positive changes in her sense of freedom,

certainty about future life, and also recorded that her Parkinson's was interfering less with important life factors.

There were some important personal contextual factors discussed in this case study. First, participant 119 had a sporadic attendance due to going away on holiday with her family for long periods of time, generally in the spring terms. As a result, this participant would often miss a large amount of the ballet classes during spring term but would still be tested before and after each term. Secondly, this participant was dealing with a variety of other medical conditions including high blood pressure, issues with cholesterol, and fibrosis in the lung. It is possible that the lack of attendance during certain periods and other health problems were impacting upon this participant's results.

8.6 Case Study 5

8.6.1 Participant Background

Participant 125 began the study in July 2013 at the age of 65. He had been diagnosed with Parkinson's for 11 years at the onset of the study and was initially assessed with an H&Y score of two, outlining that his symptoms were presenting bilaterally without any impairment to stability. With regards to other medical conditions this participant reported previously suffering from a T12 crush fracture with kyphosis in the thoracic spine and was also being treated for lumbar spine degenerative disease. As a result, this participant was removed from the biomechanical analysis of gait, which focused specifically on

movements of the upper and lower spine with inertial sensors. He was included in other quantitative measures, including the UPDRS, and thus this additional medical condition should be taken into consideration when viewing his results. He did not show any signs of dementia as assessed via the MMSE at the onset of the study.

8.6.2 *Body Function*

Table 5.14 Case Study 5 (participant 125): Changes in Body Function

Assessment	Baseline	Short Term	Long Term
UPDRS Part 1	12	9	6
UPDRS Part 3	39	40	40
UPDRS Part 4	5	4	10
Perceived Present Health	4	X	999
Perceived Severity of Symptoms	11	X	14
Perceived Stage of Parkinson's	2	X	3
Perceived Mental Health	13	X	19

Participant 125 reported that the severity of his Parkinson's symptoms slightly progressed across the duration of the study. Unfortunately we do not have data to represent this participant's final rating for perceived sense of present health (a value of 999 represents missing data) however he also reported that his stage of Parkinson's has progressed slightly. These findings also resonate with the changes in his UPDRS motor subscale scores that show this participant has progressed in his condition very slightly (1 point) in the short and long term. Progression in this instance refers to a worsening or progression of the degenerative condition.

While his UPDRS motor subscale scores demonstrated a slight progression, participant 125 saw a larger increase in difficulties with motor complications as measured in part four of the UPDRS. Questions in this subscale ask the participant about the amount of time spent in an off state (when medications are not working effectively), as well as the amount of time spent with dyskinesia. Additionally this subscale asks about the functional impact of these issues on daily activities and social interactions. It appears that these issues have become more of a problem for this participant.

At the start of his study, participant 125 reported that he had previously suffered from a T12 fracture due to kyphosis in the thoracic spine and was currently being treated for lumbar spine degenerative disease. As such, this participant was removed from analysis that focused on biomechanical analysis of spinal movement during gait. However, as the DPQ and subsections of the UPDRS scale focus on aspects other than spinal movement, this participant was still included in analysis for these measures.

With regards to non-motor aspects of daily life experiences as measured through the UPDRS part one, this participant experienced fewer difficulties with these factors by the end of the project. However, when looking at changes to emotional health, participant 125 saw more difficulties with feelings of dysphoric mood by the end of the project.

In relation to the above findings, it is important to take into consideration personal contextual factors that may have been influencing this participant's

results. At the start of his study, participant 125 noted that he was having a very stressful time. He was caring for his partner who had been diagnosed with cancer and he also had difficulties at work. He states that he did not have a lot of emotional solace or rest and found himself more frequently in off states. In the weeks leading up to his final testing session, participant 125 lost his partner to cancer.

From the start of the project, this participant discussed how he felt the dancing was doing him some good. Before the start of his research study participant 125 took part in “taster sessions” that allowed him to experience the ballet-based classes before signing up for the longer term. In one-to-one conversations with this participant after his first couple of sessions he discussed how the ballet classes were stimulating for the mind and that he felt renewed after each session. Participant 125 noted that this type of activity engages all of the senses unlike other activities he had taken part in previously.

8.6.3 *Everyday Activities*

Table 5.15 Case Study 5 (participant 125): Changes in Experiences of Daily Activities

Assessment	Baseline	Short Term	Long Term
UPDRS Part 2	9	10	12
Balance Confidence	100.00%	97.50%	98.13%
Activities of Daily Living Feeling at Wors	9	X	17

With regards to motor aspects of daily life experiences, participant 125 saw a slight trend in UPDRS part two scores towards having more difficulties with these activities by the end of the project. This finding is supported by results from subscale two of the DPQ that asks about ease of carrying out everyday activities when feeling at one's worst. Again, participant 125 saw a trend towards having more difficulties with these activities by the end of the project.

While this participant demonstrated a very slight progression of condition in his UPDRS motor subscale scores, it appears his daily activities are also showing more difficulties across the short and long term. As this participant saw improvements in non-motor aspects of daily life experiences (UDPRS Part 1), these increased difficulties with activities of daily living may be partly due to increased difficulties with motor symptoms.

Although participant 125 saw a slight drop in balance confidence in the short and long term, his confidence is still relatively strong. As discussed in Chapter Four, Myers et al. (1998) suggests that a total score above 80% is indicative of a high level of physical functioning. Participant 125 remained above 80% across the duration of the study. The decrease in confidence coincides with more difficulties in carrying out everyday activities, however the change in balance confidence is relatively small. Therefore, there may be other reasons why this participant is having more difficulties with everyday activities other than difficulties with balance. This is further supported by the lack of falls experienced by this participant across the duration of the study. As mentioned previously, participant 125 experiences frequent off states and also suffers with

dyskinesia. These issues may be playing a vital role in how he feels about motor aspects of day-to-day tasks and activities.

8.6.4 *Aspects of Quality of Life & Participation*

Table 5.16 Case Study 5 (participant 125): Changes in Aspects of Quality of Life and Participation

Assessment	Baseline	Short Term	Long Term
Sense of Freedom	4	X	6
Certainty about Future Life	38	X	32
Interference of Illness on Life	30	X	25
Perceived Quality of Life	4	X	5

When asked in the DPQ about how free he feels to do the things that he would like to do, Participant 125 reported feeling more restricted by the end of the project. This result seems to correspond to the difficulties he faces with everyday activities as discussed above.

Scores from subscale six of the DPQ show that this participant has grown less certain about maintaining a positive future life inclusive of making new friends, developing more confidence, and having hope for the future. This result is particularly interesting considering his positive view of participation in the ballet classes. For instance, in focus group discussions this participant discussed how the classes provide an opportunity for him to express himself and how being around other confident Parkinson's people is uplifting. While participant 125 is clearly seeing benefit from the classes, it appears that he still feels uncertain about his ability to maintain a positive future life. Again, personal contextual

factors must be considered when discussing these results, as it seems the loss of a loved one may have a direct impact upon how this participant feels about future life. As this participant feels uplifted when being around other confident and proactive Parkinson's people, he may be more inclined to continue participating in these types of activities in the future. However, personal contextual factors may be influencing how this participant is responding to questions asked in testing sessions and how he is experiencing the dancing.

While this participant reported feeling less certain about maintaining positive aspects in future life, he did see improvements in subscale eight of the DPQ that looked at interference of Parkinson's on aspects of present life such as personal relationships and sense of independence. It seems that although participant 125 reported having slightly more difficulties with his symptoms and with everyday tasks, he also reports that his Parkinson's is not interfering as much with other important life factors.

Throughout the course of this study, participant 125 maintained an attendance level above 90%. This finding suggests that this participant values the classes and is gaining something important from them. Data from focus group discussions suggest that he values the professional environment in which the ballet classes take place and feels that it is like being part of an "exclusive club." Furthermore, he mentions that the live music is a special element of the class and adds that it is the music that "unites the mind, body and soul."

Participant 125 also views the ballet classes as different from other activities that he takes part in (including going to the gym and playing squash) as participants are working with a piece of art. As such he states that it is a much deeper experience where participants are taking on and learning about the history and creation of the art form while also attempting to embody that work.

8.6.5 *Summary*

Participant 125 perceived having slightly more difficulty with symptoms as seen within his DPQ scores. His results demonstrated a very slight decline in his motor subscale scores and larger declines in his UPDRS Part 4 results. Interestingly he also reported having more difficulties with everyday tasks, which could relate to the increased severity of motor impairments seen within the motor subscale and UPDRS Part 4. This participant demonstrated less difficulty with non-motor aspects of daily life experiences such as difficulties with cognitive functioning and sleep however his mood slightly declined in relation to his DPQ scores. Additionally, he reported feeling more restricted in doing the things he wanted to do by the end of the study and became less certain about maintaining a positive future life.

There were multiple personal contextual factors discussed in the above case study. Participant 125 came into the project having been diagnosed with a T12 fracture with kyphosis in the thoracic spine as well as lumbar spine degenerative disease. While this participant was removed from biomechanical analysis of gait variables, these issues may have affected other measurements and played a role

in his perception of difficulties with certain tasks as well as the severity of his dyskinesia. Participant 125 attended the gym regularly and more frequently than the ballet classes. With regards to any physical improvements, it is difficult to distinguish between the physical activity he was carrying out in the gym and that which was done in the dance studio. That said, this participant did not see any large improvements in his UPDRS motor subscale scores. Lastly, this participant lost his partner to cancer after a long and stressful period of time where he had been caring for her while also attempting to cope with his own Parkinson's symptoms. These issues outside of the dance context could have influenced how he responded and presented himself at the testing sessions.

His positive outlook on the dance classes may have helped him further had he not been dealing with these contextual issues. Comments from focus group discussions and informal conversations evidenced that this participant found great significance in being a part of the ballet classes. Although he has more difficulties with sense of freedom and certainty about future life he reported feeling that his Parkinson's was not interfering as much with important life aspects. The dancing may be helping him to cope better with his symptoms.

8.7 Chapter Summary

The five case studies above evidence the necessity to consider personal and/or environmental contextual factors when looking at how people with Parkinson's respond to a dance-based intervention. These factors, including for example attending the gym regularly, not attending the ballet classes as often, other

medical conditions or injuries, and dealing with the loss of a loved one, may have a direct impact upon how people respond and perform in testing situations. As a result of considering these contextual factors, this chapter has provided a strong argument for addressing individual case studies when trying to understand the effects of dance on this group of people.

Chapter Two argued for an approach to researching dancing for people with Parkinson's that looked at the whole person, their thoughts, feelings, and ideas about their experience. Through case studies this chapter was able to take a person-centred approach that not only summarised individual results, but also considered the person and their experiences alongside their respective quantitative and qualitative data. Without considering these factors the analysis would not be complete and the findings would not be as fully understood.

Chapter Nine

Discussion

9.1 Overview of Key Findings

Chapters Four through to Seven provided a detailed description of results with reference to the ICF domains (body function and structure, activities, and participation). Chapter Eight focused on five case studies that allowed for further triangulation of quantitative and qualitative data across all ICF domains while also considering personal and environmental contextual factors. When looking at the statistical analysis of the dancing and control groups (as seen in Chapters Four through to Seven), results demonstrate a lack of significant change with regards to severity of motor and non-motor impairments after 12 months of participation in the weekly ballet classes.

Chapters Four, Five, and Six outlined potential explanations for the lack of physiological change in this study. Three key points were addressed; the first was brought forth in Chapter Four and emphasizes the need to vary methods of balance assessment in dance for Parkinson's research. This idea will be discussed further in section 9.2 of this chapter. Secondly, there is a need to understand optimal dance class frequency for this group of people. This idea will be discussed further in section 9.3 of this chapter. Lastly, there is a need to understand how specific dance movements are affecting functional motor control in people with Parkinson's. Section 9.4 will look more closely at this idea and attempt to analyse specific movements from the ballet class in relation to recent rehabilitation guidelines for this group of people.

The present thesis argued for the analysis of the dancing experience through multiple different perspectives with the aim of understanding more fully the impact that dance can have on people with Parkinson's. Through the triangulation of results interesting discussions developed about the relationships between the participants' perception of physical health in relation to the measured physical change seen in the study. This idea will be discussed further in section 9.5 of this chapter.

Chapters Five and Six found significant positive correlations between measures of motor impairments and measures of activities of daily living. However, the lack of significant change in difficulties with impairments and daily activities make the correlation results difficult to fully interpret for participants in this study. Additionally, through analysis of the UPDRS data in Chapter Six, difficulties were seen when trying to apply the ICF framework to the UPDRS scale with questions in some of the subscales crossing over different ICF domains. The application of the ICF framework to existing rating scales will be discussed in more detail in section 9.6 of this chapter.

The present thesis aimed to look at changes to aspects of quality of life with the understanding that activity participation has been closely related to quality of life in previous research (Duncan and Earhart, 2011; Everard et al., 2000). While all subscales within the Dance for Parkinson's Questionnaire (DPQ) echoed results from previous measures showing no significant changes, some of the findings warranted further discussion. For instance, although statistically insignificant, the dancing group saw a trend towards improvement in their certainty about

maintaining a positive future life while the control group saw a decline. Furthermore, the dancing group perceived that their illness was interfering less with important life aspects by the end of the project whereas control participants felt the opposite.

Additional information provided by one-to-one interviews, focus group discussions, and informal conversations suggested that there were other reasons as to why the ballet classes were valued by participants. Case studies presented in Chapter Eight demonstrated how participants valued not only the social nature of the sessions but also the cultural aspects of the class as well the enjoyment experienced when moving to live music. The music came through as being an extremely important component of the ballet classes for these participants and as such will be discussed further in section 9.7 of this chapter.

Chapter Seven discussed how the participants were keen to draw attention to the importance of social inclusion. The social aspects of the ballet class and the growing sense of a bonded community are key findings from this research and will be discussed further in section 9.8 of this chapter.

Chapter Three (section 3.4) briefly discussed how the classes encouraged participants to learn about ballet as an art form including its history as well as particular characters and storylines. Furthermore, participants (both dancing and control) were invited to the theatre as a group to watch the company perform on multiple occasions. As such, this unique project nurtured social relationships and encouraged participation in cultural experiences outside of the dance studio.

These elements of the project were greatly valued by a number of participants and were often discussed in interviews, focus group discussions, and informal conversations before and after class. These ideas will be discussed further in section 9.9 of this chapter.

While the results from quantitative measures demonstrated no significant changes across the study, qualitative data suggests that the dancing participants are gaining other benefits that are encouraging continued participation in the ballet classes and may therefore encourage participation elsewhere.

9.2 Assessing Balance in Dance for Parkinson's Research

Chapter Two argued that research may be biasing our understanding of how dance is affecting balance as studies have consistently used the same measures to assess this variable. Chapter Four explains that studies in the field have relied heavily on clinical rating scales to assess functional changes to balance. A range of studies have utilized either the Berg Balance Scale (BBS) or the Fullerton Advanced Balance Scale (FAB) to assess changes to static and dynamic balance and the majority of these studies have found significant positive improvement when using these measures (Marchant et al., 2010; Hackney and Earhart, 2009a; Hackney et al., 2007; Batson, 2010).

Chapter Four argues that scales such as the BBS do not clearly distinguish between static and dynamic balance. There is reason to suggest that measures of balance in standing (static) will not necessarily correlate to measures of balance

during walking (dynamic) and therefore these two concepts should be dealt with and potentially assessed in different ways (Moe-Nilssen, 1998; Moe-Nilssen and Helbostad, 2004). Counteracting this argument made in Chapter Four, is a study by Liston and Brouwer (1996) looking at the reliability and validity of the Balance Master, a measure to assess functional static and dynamic balance. The authors found that all dynamic components of the Balance Master were associated with BBS scores as well as measures of walking velocity whereas static components did not closely relate to these other measures of balance performance. They suggest, “specific components of the Berg Balance Scale parallel gait requirements (e.g. unsupported one leg stance, standing with one foot in front) but others address more fundamental constructs that are generally viewed as precursors to gait (e.g. raising to stand, standing unsupported)”, (Liston and Brouwer, 1996: 429). While these authors agree that dynamic rather than static balance measures are valid indicators of functional balance performance, they discuss the static components within the BBS as particularly important for gait. As such, they argue that the BBS is a valid measure of functional balance performance. However, it is important to note that the study did not demonstrate extensive test-retest reliability for the Balance Master. Nevertheless, arguments discussed in Liston and Brouwer’s paper are relevant to discussions in this work.

While the present thesis does not argue against the validity of the BBS, it does argue that studies consistently using the same measure to assess balance may be biasing our understanding of balance changes as a result of dance interventions for this group of people. While some researchers argue that measures such as the

BBS are strong indicators of functional balance performance (Liston and Brouwer, 1996), other researchers argue that dynamic gait measures are more closely related to fall risk (Hausdorff, 2009). Furthermore, this thesis has argued that scales such as the BBS do not distinguish between static and dynamic balance. Thus, it appears that other assessments may provide additional insight leading to a better understanding of the effects of dance-based activity on balance for people with Parkinson's.

The present thesis found no significant change in dynamic stability as measured via gait variability across the short and long term. Although the methods used for this study have proven to be valid, reliable measures of balance during walking (Yang et al., 2011; Moe-Nilssen 1998; Keenan and Wilhelm, 2005), these measures have not been used previously in dance for Parkinson's research. Furthermore, the methods chosen assessed balance during walking specifically and thus the results are not necessarily comparable to studies that have used clinical rating scales relying on static balance tasks (Moe-Nilssen, 1998). Future studies should aim to incorporate these measures to substantiate conclusions drawn about the effects of dance-based activity on dynamic stability for people with Parkinson's. However, researchers should be aware of the debates discussed in Chapter Four surrounding variability in gait and motor control analysis.

9.3 Frequency, Intensity, Timing and Type: The FITT Principle of training

When devising an exercise programme, the frequency, intensity, time/duration, and type of training are aspects of the activity that need to be considered.

Commonly referred to as the FITT principle, this concept helps individuals and instructors/trainers to devise an effective programme that will enable physical improvement (Power and Clifford, 2013; Shanahan et al. 2015). Frequency refers to the amount of training sessions, generally described on a weekly basis. Intensity refers to how vigorous the training sessions are and therefore how much physical stress is placed on the individual during the session. Time refers to the length or duration of activity and type or mode refers to the actual movements and exercises carried out during that activity.

The principle of overload suggests that if these above aspects of a conditioning programme remain the same, the individual will maintain a certain level of physical fitness. However, in order to improve, the individual fitness components need to be stressed to the point of overload. An appropriate amount of overload on the physiological system leads to positive adaptations, otherwise termed overcompensation (Raven et al., 2013; King and Horak, 2009). Overcompensation occurs as a result of a single or multiple bouts of training whereby the body repairs and improves beyond its previous capabilities. A variety of positive physiological outcomes arise from this appropriate overload including muscle micro-tissue repair, enhanced enzymatic activity, glycogen replenishment, and an improved cardiovascular system. However, these positive adaptations occur only when there is an appropriate balance between overload and rest (Koutedakis and Sharp, 1999).

Chapter Two discusses how recent research has argued for clearer guidelines and recommendations for the most appropriate frequency, duration, intensity, and

type of dance-based training. McNeely, Duncan, and Earhart (2015) observed that no studies to date in the dance for Parkinson's field have directly compared the benefits of different duration or intensities of dance training and as a result no clear recommendations have been put into place to indicate the most effective training regime. Volpe et al. (2013) reiterate that while it is still unclear what form of dancing is most beneficial, the amount of dancing necessary to achieve therapeutic benefit is also yet to be understood. Earhart (2009) and Shanahan et al. (2015) also discuss the lack of studies looking at the ideal frequency and intensity of dance classes for people with Parkinson's.

The aim of the present study was not to determine appropriate guidelines with regards to the frequency, intensity, duration, and type of dance class, but rather to observe physical, psychological, social, and emotional effects of an already existing weekly ballet class for people with Parkinson's. Although the researchers understood the theoretical elements of the FITT principle and the necessity for overload prior to the onset of the study, they could not influence these variables throughout the duration of the project. What has unfolded as a result of the research is an understanding that for at least some of the participants, the physiological overload was not enough in the ballet classes to elicit significant physical improvements in the chosen measurements.

With regards to specific dance for Parkinson's intervention studies, Earhart (2009) suggests that most have involved twice weekly sessions of 60-90 minutes duration that span a period of 6-12 weeks. She suggests a frequency of individual dance sessions should likely be at least twice weekly but three times a week may

be more effective and would help meet the Centre for Disease Control and Prevention (CDC) guidelines of 150 minutes of exercise per week. McNeely, Duncan and Earhart (2015) also reference the CDC guidelines and state that only one dance for Parkinson's study within their analysis met the recommended 150 minutes of exercise per week.

The *Keeping Moving* Parkinson's exercise programme devised by Ramaswamy and Webber in 2003 (Parkinson's Disease Society, 2008a), refer to the American Council on Exercise (2000) who recommend 30 minutes of moderate exercise at least five times a week. It is interesting to note that the authors of the *Keeping Moving* programme propose that there would be sufficient benefit from some of the exercises in the programme if a person with Parkinson's only did this regime once a week. This is slightly confusing given the general guidelines put forth by the American College of Sports Medicine (ACSM) (2010) stating that older adults should be involved in moderate intensity aerobic work at least five times a week (three times a week for more vigorous activity). Furthermore, as stated above the CDC guidelines suggest 150 minutes per week, which could be equivalent to 30 minutes of activity five times per week as suggested by the American Council on Exercise. However, the ACSM give specific frequency, intensity, and duration guidelines depending on the physical fitness component that the individual is trying to train (i.e. aerobic fitness, muscular strength, and flexibility). This inevitably makes it more difficult to provide a single, general statement regarding guidelines for optimal frequency, intensity, duration, and type. Furthermore, these guidelines are for the general elderly population and are not specific to those with Parkinson's. Nevertheless, it is surprising that the

Parkinson's Disease Society (2008a) would propose that carrying out their programme once per week could be sufficient given the published guidelines for exercise described above.

Shanahan et al. (2015) reviewed a total of 13 articles to understand more about what the research is telling us with regards to dance for Parkinson's. The authors go on to discuss these articles in relation to the FITT principles of training and try to conclude, based on recent research, the most effective guidelines. With regards to frequency these authors suggest that most studies support the implementation of two dance classes per week. While three studies (Heiberger et al., 2011; Volpe et al., 2013; McKee and Hackney, 2013) implemented only one dance class per week and generally saw positive results, there were some measures that did not show significant improvement. The authors state that they cannot conclude whether a longer duration, high-frequency dance class would lead to a greater magnitude of improvement and therefore further research is necessary.

With regards to intensity, Shanahan et al. (2015) discuss the difficulty with implementing commonly used exertion scales within the dance context given that "each individual's performance intensity is synchronized to the tempo of the music. For safety, the tempo of the music is usually set to ensure that individuals with the highest level of impairment are able to participate without increasing the risk of falls, and thus intensity may be progressed in line with participants' abilities," (Shanahan et al., 2015:149). Nevertheless, a variety of recent articles have made note of the progressive nature of the dance interventions (Hackney et

al., 2007; Foster et al., 2013) and Shanahan et al. suggest that this may indicate the tempo and intensity can increase once relevant motor skills have been acquired. Intensity and tempo will also differ depending on the style of dance. Furthermore, a style or tempo that works well for one individual may not work as well for another. It is also important to note that intensity is individual in nature and will be different for each individual depending on his or her physical capacity. Thus, it may be that modifications can be used to provide those who are more able with a greater challenge in the dance classes. Further investigation is needed to understand how feasible this would be and if these modifications would help to encourage overload for certain participants.

With regards to duration, Shanahan et al. (2015) state that there was little variation across the studies reviewed with respect to duration of dance class, which generally remained between 1-1.5hrs in length. The authors state that there is limited evidence to suggest that 1.5-hour classes may be more beneficial, but more research is needed to confirm. If classes are of a shorter duration, the authors note more than one class per week may be needed to gain improvement.

Shanahan et al. (2015) agree with Sharp and Hewitt (2014) and Volpe et al. (2013) that there is a lack of information about whether other forms of dance are as beneficial or more beneficial than Tango dancing. Shanahan et al. (2015) state that there have been very few studies looking at other dance forms making it difficult to understand how they compare to tango and also there is variability in the FITT principles used, making it difficult to compare.

With regards to the present study, the frequency of the ballet classes and duration of the class stayed relatively the same across the 12 months. However, the type and intensity of dancing shifted slightly to reflect the changing choreography each term. While some of the fundamental ballet movements remained the same across terms (i.e. trunk rotations, arm reaches, upper body bends), the sequences often changed with steps strung together in different ways. Furthermore, some of these movements would be used in different ways with a different intention and dynamic behind the action. Depending on the term, different gestures were used to convey a story or character. Nevertheless, the majority of movements reflected the ballet technique and did not often draw specifically on other forms of dance, such as ballroom. However, some creative tasks such as improvisation and mirroring were often included giving participants the opportunity to include their own movement ideas into the class. Additionally these creative tasks allowed participants to work in partners.

Across each term there were apparent increases in movement challenge and duration of exercises. However the results of the present thesis indicate that at a frequency of one class per week, these changes were not enough to bring about significant physiological improvement. While there was an inevitable progressive nature in the classes with regards to gaining efficiency with motor skills fundamental to the ballet technique, the shift in physiological intensity was not sufficient to elicit significant physical improvement for the group as a whole. As intensity is individual in nature, it could be that while some participants found the classes physically challenging to the point of experiencing improvements, others may have needed a more physically intense challenge week-by-week.

These ideas are backed up by interviews, focus group discussions, and informal conversations with participants that reiterate how some participants felt the dancing was a good physical workout while others felt that the classes were more mentally challenging.

As discussed previously, if the FITT principles remain the same within a training programme for an extended period of time, the physiological systems will plateau and a certain level of overload is needed to allow for further improvement. Overload can be achieved by altering the frequency, intensity, duration, or type of activity based on the individuals' needs. Greenberg et al. (2004) suggest that older adults can gain additional health benefits by increasing the intensity, frequency, and duration of activity. However, these authors note that older adults should be mindful of injuries and health. Again, it is important to note the individual nature of intensity and that while analysis of the group as a whole may have shown no significant changes, Chapter Eight evidences some cases where clinically meaningful improvement was seen in some of the assessed variables.

One could argue that given the degenerative nature of Parkinson's, a lack of significant change may be indicating that the participants in both dancing and control groups are getting enough activity to avoid degeneration of their condition. The main problem with this argument is the lack of difference between the control and dancing groups in the present study demonstrating that the weekly ballet classes are not necessarily providing anything more beneficial (with respect to the measured physical variables) than other activities that

participants were involved in across the study.

9.4 Mechanisms of Change: Training Physical Fitness Components

As discussed in Chapter Two, section 2.5, research in the area of exercise and physical activity for people with Parkinson's has been wide ranging yet still there appears to be a lack of clarity with regards to what kinds of exercises and therapies are the most beneficial for people with Parkinson's. Instead there appears to be a wealth of research outlining positive effects from a wide range of activities (Schenkman et al., 1998; Protas et al., 2005; Yang et al, 2014; Falvo et al., 2008; Hackney and Earhart, 2010a).

Again, when looking specifically at studies examining the effects of dance for people with Parkinson's it is unknown which form of dance provides the most benefit for this group of people (Volpe et al. 2013). While McNeely, Duncan, and Earhart (2015) recently carried out a review to compare different dance forms, the authors concluded that measures vary widely across studies and a lack of standardized outcome measures hinders cross-study comparisons. This statement is particularly interesting considering arguments made throughout the present thesis that discuss how relying on one or two specific measures for variables such as balance may be biasing our understanding of changes to these factors. Rather than using cross-study comparisons to determine the most beneficial form of dance, future research may want to look at including a variety of dance forms within the same study and thus assess the different forms of dance using the same measures. For instance, Hackney and Earhart (2009a)

compared Argentine Tango with other ballroom techniques and found Tango to be potentially more beneficial for certain measures. However, there is a lack of research that compares a wider variety of dance forms.

In order to understand what type or form of dancing is most beneficial for this group of people, there is a need to look at the mechanisms of change and how the movements within the dance classes may be causing physical improvement. A small body of research has looked at how dance may be impacting neural mechanisms through functional magnetic resonance imaging (fMRI) and positron emission tomography (PET) scans (Batson et al., 2014; Brown et al., 2006). These studies are needed and may help us understand what might be taking place at a neuromuscular level to encourage more fluent and coordinated movement patterns. However, this particular section of the thesis is focusing on how the movements within a dance class may impact upon components of physical fitness such as muscular endurance, strength, power, flexibility, and balance.

To date there are no studies that have measured the connections between specific movements carried out in the dance class and the resulting change on physical fitness components. Instead recent studies have only been able to speculate as to why the dancing may have caused positive change for particular physical symptoms or fitness components. For instance, as discussed at the end of section 2.5, Earhart (2009) notes that verbal cues from the instructor and auditory cues from music may prove extremely beneficial in helping people improve fluency of movement and reaction time. Furthermore this author makes note of many

functional movements often seen within a dance class including rotation in the trunk, walking in different directions and at varying speeds, shifting weight effectively to maintain stability, and mobilizing the upper and lower limbs in relation to the trunk. She suggests that training these functional movements may allow for more ease and efficiency in everyday tasks and activities.

The lack of research in this area is likely due to the difficulties researchers face in being able to extract information about particular movements and their impact upon the person with Parkinson's during class time. As discussed throughout the thesis, the ballet classes observed in the present study were not viewed as a therapeutic tool and thus the researchers aimed to be as unobtrusive as possible during the sessions. The nature of the present study and the larger research project of which it was a part meant that it would not have been appropriate to take participants in and out of class to carry out a measurement or put on/take off equipment after they had performed a specific action or exercise. This would have interrupted the flow and experience for the dancing participants thus potentially altering the outcomes and how they felt about the ballet classes. Future research that wishes to understand these specific mechanisms of change may need to prioritise this aim over other aspects of the dancing experience. It was important for the present thesis that participants fully engaged with the ballet classes and that their experience was not interrupted due to the researchers wanting to understand more than just the physical benefits.

Although there was a certain level of awareness prior to the start of the project of the need to understand how specific movements might affect physical fitness

components, the present study did not specifically aim to quantitatively assess the connections between specific movements carried out in ballet class and their effects on physical capacities due to the reasons described above. Instead we can look at how the ballet movements met different aims that have been discussed in previous research. For instance, Chapter Two, section 2.8.2 discusses commonly cited recommendations brought forth by Keus et al. (2007) outlining components that should be present in an exercise programme for people with Parkinson's. To review, these include: "cueing strategies to improve gait (visual or auditory), cognitive movement strategies to improve transfers, exercises to improve balance, and training of joint mobility and muscle power to improve physical capacity" (Keus et al, 2007:451).

Cueing strategies to improve gait both visual (demonstration) and auditory (music and verbal cues) were consistently provided in every ballet class. Participants were shown different strategies to help them remain stable and move with efficiency. They were also encouraged to feel a sense of weight by softening into a knee bend and then straightening the knees when transferring from side to side and front to back in standing sways. During walking participants were encouraged to lengthen their steps and keep the focus forward rather than down at their feet. It is however interesting to note that participants in the dance class are often encouraged to avoid walking backwards and instead taught to turn before walking in the opposite direction to avoid instability and falls. Perhaps it would be more useful to teach backward walking strategies as is often seen in Tango (Earhart, 2009). Both seated and standing exercises encouraged participants to reach their arms away from their centre of mass

through positions that also engaged the head, eye-line, and upper torso. Often these movements can cause instability and the need to oppose the reach with weight in the supporting leg(s) and use of the core muscles. Participants were not only asked to walk across the centre of the room with a partner but also walk around the dance space together at the same time. This presented a challenging situation where participants had to negotiate the space around them so as to avoid bumping into other people. During their walk participants were also encouraged to change direction quickly and incorporate gestures in the hands and arms to practice multi-tasking. These elements aim to challenge stability in motion (Batson and IADMS, 2008).

The fourth recommendation brought forth by Keus et al. (2007) suggests training regimes should work on joint mobility and muscle power to improve physical capacity. With regards to specific physical fitness components such as range of motion or flexibility, muscular strength, endurance, and power, it is difficult to say for certain if movements in the class were challenging these components for specific individuals. The reason for this is because each individual will have a different physical capacity and set of limitations. As such, what may be challenging for one may not be challenging for another. However, the present section will attempt to discuss movements that could potentially improve these components.

The ballet class included a wide range of movements that required participants to move joints through their full range of motion. For instance, axial rotation was often worked on when seated in the chair. With the hands touching the shoulders,

participants were asked to twist and rotate so that they could see the wall behind them. Once there they were asked to extend the same arm to rotation (if they were twisting right this would be the right arm) and reach even further away from the centre of the body before folding the arm back in and coming back through the centre to repeat to the other side. *Port de bras* movements (movement of the arms around the body in all planes of motion) were utilized in every class and encouraged loosening around the shoulder joints. The upper body was also taken through a full range of motion as participants were asked to roll forward to touch the floor (while seated) and then to roll up through the spine and push the chest forward to reach into thoracic extension (often while holding on to the sides of the chair to help stabilise). With regards to muscular strength and endurance, the marches and walks near the end of the class stressed these physical fitness components in the lower half of the body while *port de bras* exercises focused on endurance of the upper body and core. However, it is important to reiterate points made above about whether these actions were enough to stress these components of fitness for each individual in the class. Casual conversations with participants suggested that while some found the marches and walks near the end of the class exhausting, others questioned the need for so much repetition.

Muscular power was an element that was not as commonly trained in the ballet classes for people with Parkinson's. Training muscular power involves explosive movements that bring about maximum force at a high speed. At times, movements required participants to move quickly (stamps and claps while seated) however the force required for these movements was not as large. Some

choreography involved explosive movements or gestures, but these were not necessarily repeated enough to warrant the training of this particular fitness component.

As briefly discussed in the previous section, the Parkinson's Disease Society (2008a) created the *Keeping Moving* Parkinson's exercise programme. The programme was devised by two senior physiotherapists in the UK, Bhanu Ramaswamy MCSP and Richard Webber MCSP with the aim of pulling together information regarding the best forms of practice for Parkinson's exercise programmes. The creators reviewed relevant literature in the field and also contacted specialist physiotherapists from four centres across the UK when designing the exercise programme. They noted that physiotherapists made use of the following key components in their own programmes:

“work on postural awareness, techniques to correct poor posture, control of movement, including trunk and limbs, and exercises for weight transference and balance, requiring that people with Parkinson's exercise at a cognitive level,” (Parkinson's Disease Society, 2008a:2).

The programme is based upon the above ideas as well as 3 therapeutic models. First the 'Movement Enablement Through Exercise Regimes and Strategies' that advocates for a focus on four core areas of physiotherapy practice including gait, balance, posture, and transfers (Plant, 2000; Plant and Jones, 2001). Secondly, a model put forward by Morris (2000) for task specific training approach in the context of functional tasks. Lastly, a rationale supported by Schenkman et al.

(1989; 1998) for using a systematic approach to evaluate, interpret, and treat people with Parkinson's.

To my knowledge this work has not yet been formally published in a peer-reviewed journal. However, the information sheet is accessible for free on the Parkinson's UK website and includes a table outlining programme exercises and their aims. Table 6.1, seen below, outlines some of the exercises in the proposed programme, the aims of each exercise, and examples of exercises from the ballet class that meet the exercise aims. Although it has been argued that the frequency and intensity of the sessions were not enough to elicit physiological change, this section aims to suggest that the movements inherent within the ballet classes (the type or mode of activity) could be useful for people with Parkinson's.

Table 6.1 Examples of Ballet Exercises Meeting Aims of Keeping Moving Programme

Keeping Moving Exercise	Aim of Exercise	Ballet Class Example
Arm Reaching	Single limb arm stretch for range to arm, shoulder girdle complex (including the scapula) and thoracic spine)	All port de bras exercises encouraged single and double limb arm stretches away from the body. For instance, participants were asked to perform basic positions within the ballet technique that encouraged the arms to reach away from the body such as the arabesque line (one arm reaching side as the other reaches front). Fifth position asks participants to reach both arms above their head to form a circular shape.
Arm and Leg Stretch	Increased complexity with dual tasks to control opposing limbs for core stability and diagonal limb range	This was seen in both seated and standing exercises. In a seated port de bras exercise participants were asked to come to the edge of the chair, extend one leg side, twist the torso to the opposing side of the leg stretch, and reach the same arm as leg forward towards the side of rotation. Standing participants often worked on weight transfers and sways side to side where one leg would extend and the arms would swing and reach in the opposite direction.
Sitting posture	Posture maintenance with mental rehearsal of good alignment for sitting and standing tasks	Participants were consistently encouraged to lengthen through the top of the head and feel the sitz bones lengthening down into the chair to encourage a sense of vertical length. Warm up exercises encouraged participants to use the abdominal muscles to maintain this posture. Participants were encouraged to plant both feet into the floor and keep the knees at a 90 degree flexion when sitting in a resting position.
Sitting Pelvic Tilt	To increase range and smoothness of movement in pelvic activities of weight transference (eg. Sit to stand, walking). Strengthen axial muscles used for core stability	Specific warm up exercises encouraged participants to tilt the pelvis forward to create an anterior pelvic tilt and then oppose the action with a posterior pelvic tilt and a sinking into the bank of the chair. This was repeated multiple times and participants were encouraged to find a centre balance between the two extremes. Sometimes participants were encouraged to create circles with their pelvis.
Trunk Rotations	Improve range and freedom of trunk rotation to separate upper trunk from lower trunk for counterbalance in walking and to maintain balance in tasks involving reaching or twisting	Seated exercises asked participants to place their hands on their shoulders, draw the shoulders away from the ears, and lift the elbows to 90 degrees before rotating in the spine and trying to see the wall behind them. Once in this position participants were asked to extend the elbow of the arm closest to the wall behind to continue the stretch before coming back through the centre and repeating to the other side.

While most of the exercises and aims of the *Keep Moving* programme could be evidenced in ballet classes, a few of the suggested exercises were not as clear. For instance, the ballet class does not involve any exercises in a lying position. Furthermore, exercises such as knee rolling and stepping backwards were not as easily placed. As mentioned previously in this section, participants were

encouraged to turn and walk forward rather than walk backwards in this setting. Furthermore exercises such as the standing bend and stretch with and without knee flexion were not as common. While cool down exercises and the bow at the end of each class may have moved participants through a forward flexion in the trunk, these were not held stretches and so were not performed in the way that the programme is suggesting.

The above point opens an interesting discussion in that although many of the exercises proposed in the *Keeping Moving* programme can be seen at one point or another throughout the ballet class, these actions are integrated into a sequence of movements performed to music. As such participants are moving through these actions rather than completing a certain amount of repetitions and sets as is often seen in a conditioning or physical training programme. For instance, participants may find that they are rotating the torso in a standing position (as is suggested in the *Keeping Moving* programme), however they may find themselves rotating once more to the other side before moving on to another movement that does not incorporate rotation at all. In this way, the ballet classes are incorporating similar body actions but are using them in a different way to the proposed programme. Further investigation is needed to understand how the two different ways of working will impact upon the person with Parkinson's and if one presents more physical benefit.

Although some of the proposed exercises were not necessarily addressed in the present ballet intervention, there is no reason why these exercises could not be included in future sessions. However, lying exercises are not often seen in

traditional ballet technique classes and so this may warrant further discussion.

Singh et al. (2006) carried out a study to look at the relationship between physical fitness components and functional performance in older adults living in care facilities. These authors suggest that there is a lack of research that investigates these specific relationships, even though authors tend to identify how certain fitness components such as balance are important for mobility tasks. Singh et al. (2006) found a considerable difference between males and females with regards to physical fitness components that were important for functional tasks. For the men, the main predictors of functional performance were measures for coordination, with minor contributions of measures of muscle strength. In women, measures from all domains were predictors of functional performance, with coordination and flexibility playing a major role. These findings suggest that men and women may rely on different components of fitness to achieve functional performance of various everyday tasks, such as rising from a chair or walking forward for eight meters.

The arguments brought forth in Singh et al.'s study support arguments made throughout this thesis with regards to the importance of functional limitations and how these might impact upon participation. While it is necessary to understand the mechanisms of change and how specific movements/exercises are impacting upon various physical fitness components, there is also a need to understand what these changes mean with regards to functional performance and ability to participate in activities (McGill, Houston, and Lee, 2014).

After reviewing the material discussed in this section it is evident that there appear to be no clear set of guidelines specific to dance interventions. Rather, studies that have looked at the benefits of dance for this group of people have often needed to refer to exercise and physiotherapy guidelines for recommendations of best practice. As more and more dance forms are introduced to the field, there is an increasing need for researchers, instructors, and participants to understand what kinds of dance offer the most physical benefit for this group of people. As discussed in the beginning of this section, in order to achieve this understanding research needs to look at the specific movements within the dance-based activity and their relationship with improved physical fitness components. Furthermore, there is a need to look at the relationship between movement and music in relation to the improvement of these physical fitness components.

9.5 Perception of Physical Change vs. Measured Physical Change

Chapter Eight comprised of five case studies demonstrating a more detailed triangulation of information across the full breadth of data collection methods used in this PhD. The case studies presented an opportunity to discuss the relationships between different variables across the ICF framework but also unveiled some discrepancies between results from various assessments. For instance, the participant described in case study one demonstrated a strong improvement in her UPDRS motor subscale scores with a change of eight points. However, the DPQ results show that she rated her physical symptoms and present health as having become slightly worse across that same time period.

Interviews and focus group discussions with this particular individual demonstrated that she was more able to discuss perceived physical improvements in other members of the ballet class and talked more generally about how the movements in class would be helpful for people with Parkinson's. However, she did not often refer to herself and the physical changes that she felt she had experienced as a result of the dance classes.

In contrast to the above, the participant described in case study four demonstrated a slight decline or worsening of motor impairments across the duration of the study. However, her results from the DPQ suggest a slight improvement in the perception of her Parkinson's symptoms. Furthermore, the one-to-one interview suggests that she thinks there may be a slight improvement, but again this participant finds it difficult to say for certain if things have changed for the better as a result of dancing.

The above case studies demonstrate that participants' perceptions did not always coincide with the measured effects. The concept of perception in this instance requires further clarity. There are two ways that perception can be viewed in the context of this discussion. Interviews, focus group discussions, and informal conversations encouraged participants to discuss their perceptions about how the dancing was benefiting them in all aspects of their life. Thus, participants discussed with the researchers their perceptions of change across time. While questionnaires used in the study, such as the DPQ, ask participants to rate their perception of factors such as severity of condition and difficulties with everyday tasks, they are not assessing the participants' perception of change. Rather they

are assessing the participants' perception of his or her health at a given moment in time. As participants likely would not recall what they had recorded previously, here they are not providing their perception of change but rather providing a rating of their health at that moment. Stemming from these results, researchers can state that the participants reported their perception of a particular health variable at a specific moment in time. From this researchers could then suggest that there may have been a change in their perception of a particular health variable. As such, perception of change was assessed qualitatively in this study via interviews, focus group discussions, and informal conversations but the other assessments, including questionnaires, are examples of the measured change in this study.

Schenkman et al. (2002) investigated patients' perceptions of Parkinson's symptoms and difficulties with functional tasks across a three-year period. This particular study focused on perceptions of symptoms at a given moment rather than across time or during an intervention study. A total of 109 participants took part in at-home interviews that included both structured questions as well as open-ended questions. The results suggested a disconnection between the participants' responses to open-ended questions about the disorder, compared with their responses to questions structured by the investigators. For instance, when responding to structured questions about difficulties with specific motor impairments, a majority of the participants acknowledged rigidity and bradykinesia, and more than 40% reported tremor. However, few respondents noted those same impairments as being among the "worst aspects" of the condition and fewer than 10% identified any impairment in response to the

following open-ended question.

“We are interested in knowing more about PD (Parkinson’s Disease) than can be captured through a list of signs and symptoms. Please tell me what you consider to be the worst aspect of PD (Schenkman et al., 2002:792)”

These findings are particularly interesting when referring to results from the present study with regards to some of the discrepancies between participant responses in structured questionnaires (measured change) compared to their responses during interviews, group discussions, and informal conversations (perceived change). While participants often noted in interviews a general sense that the ballet was doing them some good, results from structured questionnaires did not always show this to be the case. Findings from the present thesis are supported through recent research conducted by Westheimer et al. (2015). Results from the study demonstrated that in interviews, participants reported positive benefits related to quality of life and well-being as a result of dancing, however these results were not reflected in the quantitative assessment of these variables (Westheimer et al., 2015). The authors concluded that some of the standard instruments often used within this field of research and that were also included in the above study (the BBS and PDQ-39 among others), did not appear to capture the full benefits of dance for the participants. Thus, the interviews proved to be a useful tool in helping to gain further information and understanding.

It is also interesting to note that while participants in Schenkman's study acknowledged both impairments and functional limitations in response to structured questions, the open-ended question demonstrated that participants were more likely to identify functional limitations as particularly burdensome while rarely identifying impairments (Schenkman et al., 2002). The authors of this study suggest that these types of investigations can "illustrate the importance of understanding the impact of disorders from the perception of the patient," and thus "are critical to researchers because they clarify further the processes and impact of disablement," (Schenkman et al., 2002). This finding emphasizes the need to understand the lived experience by the participant and what is important to them. While health care professionals and researchers may focus more heavily on physical impairments, participants may place more value on the difficulties they face with functional, everyday tasks. The present thesis has argued for a more holistic approach to dance for Parkinson's research that considers the difficulties patients may face with activities of daily living and participation in life situations alongside physical and mental impairments.

Schenkman et al. (2002) also saw that by the end of the project, fewer participants acknowledged problems across all of variables being assessed. This is an interesting finding given that the participants were not given any particular treatment nor were they involved in a particular intervention regime. However, the study does not report on medications participants were taking or other activities that participants were involved in during the course of the project. It could be that these other factors were having a positive effect. In any case, the authors suggest that the participants possibly adjusted to cope better with their

Parkinson's and were no longer as aware of specific impairments, functional limitations, and the emotional burden of the condition. Other research has also noted that one's perception of disability is relative and can shift based on experience and expectations (Daltroy et al., 1999; Schenkman et al., 2002; Starkstein et al., 1998).

The above studies are relevant to findings discussed in Chapter Seven of this thesis, particularly to results surrounding changes to interference of illness on important aspects of life. Results from this part of the PhD study found that although the dancing participants reported their symptoms as being slightly worse by the end of the study, they also reported less interference from their illness on aspects of life such as maintaining a sense of independence, personal relationships, and a sense of self-efficacy. Although participants saw a decline in perceived severity of symptoms, results suggest that they did not view their Parkinson's as being as much of a burden to them by the end of the study. However, the changes discussed above were statistically insignificant and further investigation is needed to substantiate conclusions about the relationship between impairment and illness interference.

Interviews, focus group discussions, and informal conversations with the participants suggest that in general, there is a sense that the ballet classes are doing them some good, even if the specifics are not easily verbalized. Although some participants found it easier to discuss how other members of the group were seemingly improving, the perception of improvement as a result of the ballet classes was still present in discussions. It is unsurprising to see that

participants taking part in the ballet sessions felt the dancing was causing some physical benefit. The participants were aware that they were part of a study looking at the potential effects of dance for people with Parkinson's and as such understood that the dancing was being viewed as an alternative treatment option. If we consider the nature of the placebo effect, there is a possibility that participants believed in the treatment so much that they actually felt physical improvement in themselves. The NHS describes this phenomenon as "an example of how our expectations and beliefs can cause real change in our physical bodies."

McRae et al. (2004) found that participants who perceived that they had received transplant surgery (specifically, stereotactic implantation of human embryonic dopamine neurons into the brain), consistently reported better quality of life (QOL) than those who perceived they did not receive the treatment. Furthermore, the results indicated that perceived treatment was more strongly related to quality of life outcomes for the duration of the 12-month double-blind study than was the actual treatment they received. The authors concluded that as a result, the placebo effect appeared to be very strong in this study.

Within the present study it appears that the perception of physical change was more than simply a strong belief in the dance intervention and what it could possibly provide. As mentioned previously, participants consistently made note of how they noticed other members of the class moving more fluently and with better coordination and control. When participants in the focus group discussions were asked to watch video playback of some of the dance classes, all participants

agreed that the group as a whole had seemingly improved across time. Along with participants, the ballet instructors, researchers, student volunteers, and other guests who joined the classes at various points throughout the study frequently expressed their amazement when participants walked across the space to the music and appeared to be free of their Parkinson's symptoms. Again, the perception that participants' gait patterns had drastically improved did not coincide with results from the quantitative gait measures. However, the music and other external auditory cues were likely having a positive effect on participants gait patterns in this context (please see section 9.7). Nevertheless, it seems that it was not only a strong belief that the dancing would be doing some good physically, but also the fact that participants were actually seeing improvement in their peers during the sessions. Witnessing these moments of fluent and graceful movement in an individual who usually moves in a jerky and uncoordinated manner may impact upon the participants' belief that the dancing is physically beneficial. Furthermore, seeing other people of a similar age and a similar condition successfully complete a challenging task can have a direct impact upon an individual's self-efficacy.

Self-efficacy is defined as an individual's belief in his or her capability to meet the demands of a specific task or goal (Bandura, 1977). As such, self-efficacy is a situation-specific form of self-confidence. Bandura's self-efficacy theory states that there are four main sources of efficacy information for the individual. These sources include performance accomplishments (having successfully completed something similar in the past), vicarious experiences (seeing someone who you view as being similar to you accomplish the task), verbal persuasion

(encouragement from teachers and peers), and emotional arousal (reducing anxiety and managing physiological arousal states). Interestingly, self-efficacy plays an important role in one's motivation to carry out an activity. The Self Determination Theory (Ryan and Deci, 2000) states that in order for an individual to be intrinsically motivated to carry out an activity, three fundamental basic needs need to be met; these include autonomy, competence, and relatedness. Autonomy suggests that the individual had some choice in the matter (both in deciding to take part in the activity and choice within the activity itself), competence suggests that the individual needs to feel capable of carrying out the activity successfully, and relatedness suggests that individuals need to feel connected to others in the environment. If all three basic needs are met, the individual is far more likely to be intrinsically motivated to carry out the activity.

In relation to the present study, the above theories are important when reflecting on the participants' tendencies to watch others in the class. As mentioned previously, participants were more able to talk in interviews, group discussions, and informal conversations about how other people in the class were seemingly improving. While the aim of the researcher was often to discover if participants felt that they had experienced any physical change within themselves, the tendency for participants to discuss other people's achievements could be representative of a source of self-efficacy through vicarious experiences. Furthermore, by seeing this improvement and possibly feeling improvement within themselves, participants may be more motivated to continue attending the dance sessions.

While the perception that the ballet classes were doing some good physically were not necessary supported by some of the physiological tests in the present thesis, the ballet classes were presenting opportunities for participants to feel better about their physical capabilities and accomplish challenging tasks.

9.6 Applying the ICF Framework to Existing Assessments

A main aim of this doctorate research was to propose and use the World Health Organisation's International Classification of Functioning, Disability, and Health (ICF) as a methodological framework. Chapter Two, section 2.8, argues for the inclusion of such a framework to help researchers better understand the physical, social, emotional, and social benefit of dance for people with Parkinson's. Chapters Four through Eight describe the results from the present PhD project in relation to the various domains of the WHO's ICF framework.

A difficulty that surfaced across the duration of the study was the apparent disconnect between some of the measures used within the present thesis, some of which have been used in other dance for Parkinson's studies, and the main ICF domains. For instance, Chapter Six reflects on the UPDRS, and in particular part two of this scale that asks about motor aspects of daily life experiences. Within this subscale, some items appear to be more representative of problems with body functions (the first domain of the ICF) such as changes to tremor, excess saliva, and drooling whereas other items are more representative of the second domain of the ICF, activities of daily living. This chapter argues that although the scale appears to cross over two different ICF domains, the questions in this

subscale that appear to be more reflective of the first ICF domain are not necessarily assessing body functions but rather asking participants about difficulties they face with these issues in an average week. Thus, the scale is generally more representative of the second domain. Even still, tremor, excess saliva, and drooling are not clear examples of functional everyday activities and therefore the confusion of what falls under what category still remains.

Section 2.8 of the literature review discussed arguments brought forth by Jette (2006) stating how critical it is that the three domains of function, activity, and participation are made clearly distinct from one another so that they are measurable in their own right. Arguments brought forth in the literature review suggested that while Jette argues for a framework that has clearly distinct domains, in the context of dance for Parkinson's research, these boundaries might exist but overlap. It was thought that this overlap need not be a problem but rather a strength of the framework allowing researchers to look at variables from multiple different perspectives.

There is a need to clarify arguments made in this section of the literature review given the difficulties discussed above. As certain factors such as gait and balance may fall into more than one ICF domain (i.e. walking is a basic function of the body but can also be viewed as an everyday activity), there is even more of a necessity for the domains to be clearly distinguishable from one another. Thus far the thesis has not necessarily argued against Jette (2006) with regards to the need for clearly distinguishable domains. Rather the thesis has argued that the overlap of domains is not necessarily problematic but rather could be a strength

of the framework. After completing the research this thesis is continuing to argue the same viewpoint and further emphasize the need for clearly distinguishable domains. In other words, the overlap is not necessarily problematic as long as the domains are distinguishable from one another and the researcher can be clear about when a certain variable falls into a particular category.

To allow proper use of the ICF framework, the various domains need to clearly state what makes them unique and distinguishable from other domains. For instance, the arguments made above with reference to part two of the UPDRS were structured through reviewing various documents outlining the framework. It was only after reviewing several documents that it became clear how one could possibly distinguish between assessing body function and structure and assessing difficulties with these issues during daily activities. However, these arguments or ways of distinguishing between domains may not be as accurate to what the WHO intended. In order to properly use the ICF framework and assess variables in a way in which the WHO intended, there is a need to discuss the domains in comparison to one another and reflect on the distinct characteristics of each.

It is however important to note at this point in the discussion that the present thesis is using the ICF as only a framework for research and is not using the classification system and its qualifiers that are specific to the model. The WHO state that, “The list of domains in ICF becomes a classification when qualifiers are used. Qualifiers record the presence and severity of a problem in functioning at the body, person and societal levels,” (WHO, 2002:11). While the general domains are being used as a framework for this research, qualifiers have not been

used to assess severity using this tool. Rather other measures and tools, specific to elderly and Parkinson's populations, have been used and placed accordingly within the ICF framework. This is not the only study to use the ICF in this way and other recent studies, such as Dibble et al. (2010) and Ellis et al. (2011) have attempted to do the same. In either case, the blurred boundaries between the definitions and domains can still present problems.

Some models of the ICF framework discuss activity and participation as if they were categorized under the same domain. For instance, within the WHO's 2002 document entitled, "Towards a Common Language for Functioning, Disability, and Health," the chart that sets out the full list of chapters on page 16 addresses activity and participation together with chapters that cross over both concepts. However, the definitions set out on page 10 of this document clearly define activity and participation, and limitations of both, as distinct from one another. Furthermore, the commonly used model as seen on page nine of the WHO document and also used within this thesis, show activity and participation to be completely separate from one another to form three main domains, impairment, activity, and participation with contextual factors listed below. While activities refer to the execution of specific tasks, participation refers to the individual's ability to take part in life situations. However, there may still be confusion with what is representative of a task or a life situation. For instance, the WHO (2002) suggest that difficulty gripping an object is an activity limitation as is an individual being incapable of taking public transportation. The former example involves one specific physical task or action while the latter involves a wider range of issues and puts the individual in a public, social context. As such one

may argue that taking public transportation represents involvement in a life situation and therefore is more reflective of participation. In these situations it can be difficult for a researcher to understand how to use the framework and its domains in the way in which it was intended.

As a result of the above arguments, the present thesis used the ICF in a way that made sense for the project and justifications for those decisions have been presented throughout. While trying to stay within the boundaries that had been set by the WHO with regards to the various domains, at times there was a need to clarify how and why certain measures and their outcomes belonged in a particular domain for the context of the project. This was needed because none of the chosen assessment methods for this study were created in light of the ICF framework and with the aim of achieving assessment at all levels of that framework. For instance, the Dance for Parkinson's questionnaire (DPQ) created by McRae and Rubin was designed to better understand changes to aspects of quality of life for people with Parkinson's after a dance intervention. The authors had no intention of trying to cover a range of ICF domains however the present study aimed to associate the various subscales with either impairment, activity, and participation. Again, a certain amount of license was required to justify why the various subscales were more representative of those domains for that particular situation.

9.7 Moving to Music

In the case studies described in Chapter Eight, four of five participants noted the significance of the musical accompaniment. Focus group discussions and informal conversations continued to unveil the importance of music and how moving to music appeared to help alleviate Parkinson's symptoms. As mentioned previously, it was not only the participants that noticed a change but also observers of the ballet sessions and other members of the class including caretakers, the dance instructors, researchers, and guests.

The participant described in case study one felt that the music helped members of the class to walk in a more coordinated and fluent way and may also help people to maintain a good walking speed. She also felt that the music was a motivating element of the class and found that she responded well to it. The participant described in case study two felt that it was the music that encouraged people to continue to attend and enjoy the ballet sessions week by week. She also discussed an innate tendency to want to move the body when music was played. When asked why one might want to dance over other physical activity forms this participant said that for her, it is the music. In focus group discussions this participant discusses how important live music is to the dancing experience. While she understands that it is not always feasible to have live musicians playing for the dancers, she states that there is a flow that is not present when the teacher must start and stop the music on a machine. Furthermore, she felt that there was an important dialogue present between the dancers and the musicians when they were performing live.

The participant described in case study four suggested that it was a combination of things that made the classes so special and important to her. She states that the dance, the music, the personalities and people in the class, as well as the general atmosphere all play a role in making it a pleasant experience. She also felt that the music is what makes dancing stand out from other physical activities and may be a motivator for continuing to attend the sessions. She also agrees with the participant described in case study two and makes reference to the tendency to want to move her body when music is played. The innate desire to move the body to music has also been well documented in research (Koepchen et al., 1992; Grewe et al., 2007; Hodges and Sebald, 2011). As mentioned in Chapter Eight, the participant described in case study five feels that the live music is a special element of the class. He feels that moving to music “unites the mind, body and soul.” Other members of that focus group who were also involved in the research for this PhD study suggested that the music had the power to lift their spirits and create a magical experience.

In his book entitled “Musicophilia,” Oliver Sacks writes about this particular phenomenon where people who are suffering from a particular motor impairment have used music to help alleviate their symptoms. He recalls a particular situation that he experienced after a climbing accident that resulted in him tearing the quadriceps tendon from his leg rendering him unable to walk. Once able to put weight back on his leg during his rehabilitation he realised that the “natural, unthinking, spontaneity, the automaticity of walking” had completely left him (Sacks, 2011:255). Upon recalling the music from a cassette tape that he had recently been given of Mendelssohn’s Violin Concerto in E Minor, he found

the natural rhythm and melody of walking came back to him and with this, a sense that his leg was alive and a part of him again. Earlier in this text Sacks refers to this recall of music as ‘musical imagery’.

In his book Sacks (2011) reviews multiple case studies of individuals who suffer from Parkinson’s but have found that music helps them to move more fluently, as if they were no longer with Parkinson’s. He discusses how even the thought of a musical score (musical imagery) has helped patients out of a complete freeze and allowed them to resume a “blissful ease and flow” in their movement (Sacks, 2011:275). It is interesting to note that Sacks (2011) refers to dance as being the ideal combination of music and movement. He suggests that both music therapy and exercise have shown to be beneficial for this population and thus a blend of the two would seem to be the ideal activity for those living with Parkinson’s.

With regards to the present study, observations of the ballet classes as well as conversations, both formal and informal, with participants have shown that the change in movement can be quite dramatic during the walking section of the class. At this point in the session, participants are asked to line up along either side of the room and face one end. As they reach the top of the line they are to join up with a partner in the middle of the space and walk together to the other end of the room. Accompanying their walk is a strong pulse provided by the musical accompaniment and verbal cues from instructors encouraging them to stride out and increase their step length. Others around them are encouraged to move their feet to the beat of the music, even if only on the spot, and participants often clap along to the rhythm as well. These external auditory cues appear to

help participants to achieve a more steady, rhythmic gait pattern in the moment and it is these moments that participants and observers generally comment upon.

One of the main problems with gait in people with Parkinson's is deficient internal timing that disturbs the natural rhythmic locomotion (Ebersbach et al., 1999, Thaut et al., 2001). Nombela et al. (2013) refers to earlier work by Thaut et al. (1999) when suggesting that although both visual and auditory cues may help to improve gait, the auditory system may be more useful for two main reasons.

“(i) reaction times for auditory cues are 20–50 ms shorter than for visual or tactile cues; (ii) the auditory system has a strong bias to detect temporal patterns of periodicity and structure, compared to other sensory systems,” (Nombela et al., 2013:2565).

Nombela et al. (2013) state that the combination of the temporal sensitivity within the auditory system paired with the strong rhythmic characteristic of music may provide a useful temporal input for the motor system. These authors suggest that the improvement of Parkinson's gait as a result of external regulatory rhythmical cues or stimuli has been known for quite a few years. Early studies, such as one by Rossignol and Jones (1976) described functional connections between the auditory and motor system. Research carried out by Thaut et al. (1996) described how rhythmical auditory stimulation could influence the motor system in Parkinson's patients, thus improving a variety of gait variables including speed and stride length. De Dreu et al. (2012) performed a meta-analysis of randomized controlled trials that looked at music-based

movement therapy (MbM-therapy) for people with Parkinson's. Interestingly the results revealed a significant improvement in walking velocity for gait-related MbM-therapy, but not for dance-related MbM-therapy. However, the authors of the study still promote dance-based activity for people with Parkinson's given the multitude of other beneficial effects that have been noted in recent research including improvements in standing postural balance. Furthermore the authors reflect on work by Blood and Zatorre (2001) stating that moving to music activates the release of endorphins in the brain leading to feelings of pleasure. As such music can elicit emotional responses and may distract the participants from other elements of exercise such as fatigue.

Through neuroimaging techniques, recent studies have revealed increased coupling of neural activity between the auditory and premotor cortex during rhythmic processing (Chen et al., 2006; Grahn and Rowe, 2009). It is interesting to note that areas of the brain responsible for rhythmic processing are closely related to those involved in the production of movement, and thus are also affected by Parkinson's. For instance, the basal ganglia, an area of the brain affected by Parkinson's, is involved with the sequencing of rhythmic events in the body (McIntosh et al., 1997). Therefore, it seems that the rhythmic impetus provided by the auditory cues may then help to drive motor rhythmic action that has otherwise been lost (Chen et al., 2008). Thaut (2005) discusses results from research in the field (Thaut et al., 1998; Large et al. 2002) and suggests that auditory rhythm communicates "stable, interval-based temporal templates to the brain, to which the motor system has privileged access even below levels of conscious awareness," (Thaut, 2005:43).

Del Olmo and Cudeiro (2005) looked at changes to temporal variability of a range of gait parameters including cadence, stride length, and speed as a result of participation in a physical rehabilitation programme based on rhythmic sound cues. The one-hour sessions took place five times a week for a period of four consecutive weeks. The authors found that those who took part in the programme displayed a significantly reduced variability in comparison to control subjects. The above study supports the use of rhythmic auditory facilitation in Parkinson's and suggest that it could be a valuable tool for improving gait timing in this group of people. While participants in the present study observed changes to gait patterns during the sessions when walking to music, the dancing and control groups did not evidence a significant change in gait variability during testing sessions when music was not present. However, the high frequency of sessions over a short duration in del Olmo and Cudeiro's study may be a reason why such a significant change was seen.

In his 2005 book entitled, "Rhythm, Music and the Brain: Scientific Foundations and Clinical Applications", Thaut describes the fundamental role that arts have in the optimal functioning of the brain. He likens the arts, and in particular music, to a specific kind of perceptual language that engages and regulates the arousal and activation of the physiological body systems. Thaut postulates that artistic expression may exercise fundamental brain functions and that it, "may create unique patterns of perceptual input that the brain needs and cannot generate through other means in order to keep its sensory, motor, and cognitive operations at optimal levels of functioning," (Thaut, 2005:25). From an anthropological perspective, many societies throughout human history have used music to

express emotions and feelings, and to help bring people together playing a role in their interactions (Thaut, 2005; Mithen 2006). Furthermore, music is commonly used symbolically to represent beliefs, to mark special events in one's life, in social rituals, and in expressing or supporting societal views (Thaut, 2005). Thus, the somatic connection to music is more than an unconscious link between auditory and motor systems, but is an integral part of life and the human experience. It can call upon memories that elicit certain feelings, thoughts, or moods, and can act as a form of communication of ideas.

Overall there is evidence to suggest that moving to music can have a positive effect on movement for people with Parkinson's. While it is clear that music was perceived to be having a positive effect on movement for participants while they were taking part in the ballet classes, the measures within this PhD study suggest that these benefits were not necessarily evidenced as strongly when being assessed outside of the dance context.

McIntosh et al. (1998) carried out a pilot study investigating long-term effects of rhythmic gait training. After three weeks of daily training, participants maintained improvements for up to three to four weeks after the cessation of the intervention. With regards to the present thesis, it could be that more exposure to dancing and moving to rhythmical cues could be beneficial however further investigation is needed to understand if this would be the case. Furthermore, research suggests that the type of music and rhythmical variations can have differing effects and it is dependent on the individual as to what works best for them. When the music is slower than the individual's preferred gait speed or is

too cognitively demanding or complex, the beneficial effects of music on movement may not be seen. In these cases attention is diverted to these issues and the automaticity of movement may be lost (Nombela et al., 2013; del Olmo and Cudeiro, 2005; Brown et al., 2009). Thus, it appears that the tempo and rhythm are important factors to consider in helping people with Parkinson's to get "into a groove" and experience the beneficial effects of music on their physical movement patterns.

9.8 Socialization and Communication

Common motor and non-motor impairments often experienced by people with Parkinson's were brought forth in Chapter Two (section 2.1). This section made reference to Cummings (1992) who suggests that the myriad of difficulties that people with Parkinson's face on a daily basis can lead to social isolation and feelings of loneliness. Furthermore, people with Parkinson's may feel embarrassed about their symptoms and may lack a certain amount of self-efficacy in particular situations. Focus group discussions and informal conversations in the present study led a couple of participants to explain experiences where they have felt embarrassed when participating in day-to-day tasks. One participant made note of how he was once escorted out of the shopping centre because the surrounding people mistook him for someone who had been drinking alcohol. Another participant recalled an experience at the bank where the bank teller counted money in front of him so slowly that it felt patronizing for that individual. These examples suggest that it can be difficult for the person with Parkinson's to participate normally in society when society itself

is not aware of the condition and may treat people with Parkinson's differently to the normal person. The ballet classes provided an opportunity for people with Parkinson's to participate within a community that fully understood their condition but that also did not dwell on the condition itself. As discussed in Chapter Three, the classes did not focus on Parkinson's and the need to treat certain symptoms but rather focused on learning about the art of ballet.

It is interesting to note results from Chapter Seven that show a marked improvement for the dancing group with regards to subscales six and eight. As discussed in Chapter Seven, subscale six asks participants about certainty in maintaining a positive future life inclusive of making new friends and developing a sense of community with other Parkinson's people. Subscale eight asks participants about the level of interference of their illness on important life aspects such as their personal relationships and ability to work or contribute in society. These two subscales are the only subscales within the questionnaire that explicitly describe aspects of socialization and personal relationships, other than subscale 10 which was removed from this particular study as control participants could not respond to questions within this subscale. Although results were insignificant, the dancing group saw improvements in these two subscales that the control group did not see.

Individuals from all five case studies describe how the social aspect of the sessions is of great importance to them (see Chapter Eight). The individual described in case study one discusses how it is nice to just go to the sessions to be with people and people who are generally cheerful and happy when they arrive.

In her interview this participant also discusses how people in the class seem to notice when others are doing well and they comment upon it. This participant seems to appreciate the support and encouragement from her peers in the class. In a focus group discussion the participant described in case study two says that the dancing is special and different to other activities because of the sense of community that has developed throughout the project. She discusses how the group has developed to become like a family.

The participant described in case study three presents an interesting observation in his one-to-one interview. He says that the ballet classes are providing a useful topic of conversation for other social interactions with his friends outside of the dance context. He says that his friends are generally intrigued by the fact that he is dancing and taking ballet classes at a professional institution. In a focus group discussion he also states that he enjoys going to the theatre with the group to see live work and performance. The participant described in case study four immediately emphasizes the importance of the group in her one-to-one interview. She says that the dancing makes her feel happy and mentally good but it is also the people that make her feel this way. This participant was keen to state in her interview and also during informal conversations how much it meant to her to go to a place where she felt genuinely wanted and that people were happy to see her. Later in her interview she says that being with people motivates her to be active and exercise.

In a focus group discussion the participant described in case study five says that he feels like he is part of an exclusive club and that being together and dancing in

professional institution is part of what makes the classes special for him. During this same focus group discussion a member of staff from Parkinson's UK attended the discussion group. This individual attended the ballet sessions on a weekly basis and helped to organize tea and biscuits after each class. He is immersed in many Parkinson's support groups and knows the participants who were involved in this project well. He says that the class has evolved and that there is now a whole community where participants are connected in different ways outside of the dance studio as a result of this class. He says that attending the theatre as a group and watching the company perform has been an impetus for this increased socializing outside of the dance context.

In general participants discussed a number of different aspects of socialization including the support and encouragement they receive from peers, the enhanced communication that was not just verbal but also tactile (holding hands), and the joy of making new friends and building relationships.

The social benefits of dance for people with Parkinson's have been documented in a few recent studies. Hackney et al. (2007) found that tango dancing appeared to be a way towards helpful human interaction. Tango dancing involves a certain amount of touch and embrace with your partner. The authors state that the sense of community was evident when the tango group requested to have lunch together when some participants were nearing the end of their 20 lessons within the study. The authors also note that the progressive learning aspect of Argentine tango along with the touch and the increased socialization all help to demonstrate an appropriate and enjoyable activity for both healthy elderly individuals and

those suffering with Parkinson's. Progressive learning and continued education in adulthood will be described in further detail in the next section of this chapter.

In their study looking at the effects of contact improvisation for people with Parkinson's, Marchant et al. (2010) state that contact improvisation promotes continuous tactile connection between dance partners. In their study, several participants reported in casual conversation that the physical contact was one of the most valuable things that they gained from the experience. The authors state that contact improvisation can offer an activity that provides a high amount of mutual human contact that is not inherently combative or sexual in nature and thus, the activity may be helpful for a wide range of populations, including those with Parkinson's.

As discussed in Chapter Two, Heiberger et al. (2011) used the Quality of Life Scale (QOLS) to understand changes across an eight-month time period. The items that changed for the better as a result of taking part in the dance classes included recreation, socializing, relationships, and helping and encouraging others. In their article, the authors refer to presentations and talks held at a workshop in November of 2008 at English National Ballet studios. The authors discuss that their results (Heiberger et al., 2011) help to support comments made during the workshop stating that social interactions can enhance the motivation to attend the dance classes, even when patients are not feeling that well.

A study carried out by Foster et al. in 2013 looked at changes to activity participation as measured by the Activity Sort Card (ASC) as a result of

participation in tango dancing. The above authors state,

“the social interaction, social support and social influences that emerged from the tango classes likely also had positive effects on participation. Participants in the Tango group reported engaging in social activities together outside of class, including attending a play, the symphony, and a social dance (Foster et al., 2013:7).”

Foster et al. (2013) also note that the presence of a partner may have helped people to feel more comfortable challenging themselves with complex and difficult movements. Interestingly, the participant described in case study one also noted in her one-to-one interview that she noticed a change in how people move when they are in contact with a partner. She references a particular individual in the class who usually has difficulty moving independently but gains the courage to walk across the studio when holding hands with other people. Foster et al. (2013) discuss how this support may lead to mastery experiences and thus may be a primary source of self-efficacy that can encourage participants to engage in more or new activities that would provide the same sense of accomplishment. Section 9.5 discussed how self-efficacy might have also been nurtured through vicarious experiences and watching others successfully complete various motor tasks.

Overall there is sufficient evidence to show that dance, in a variety of forms but inclusive of ballet, can promote and nurture socialization and personal relationships for this group of people. While exercising with a group of people

who are dealing with a similar condition is certainly a part of this socialization, the content of the dance classes also encouraged communication and expression. As discussed in Chapter Seven, some of the ballet exercises asked participants to hold hands and work in partners. At the end of every class the participants would gather in a circle and hold hands while passing around a tight squeeze to the person standing next to them. The squeeze was a way for participants to say thank you to their fellow peers for attending the class and dancing alongside them. This was often regarded as both a valued and emotional part of the class. Improvisation work encouraged participants to create their own movement sequences, often focusing on movements of the upper body, while their partner tried to mirror their actions. In this way the two dancers are working very much together as one leads and the other follows.

Ballet often involves telling a story through mime. Participants learned about various different gestures and actions used within the ballet performance and what the movements represented. They were encouraged to express themselves using body language and gesture rather than words. The instructors also encouraged participants to make eye contact with others in the room during both seated and travelling exercises. These gestures and the encouragement of eye contact with others in the room allowed for another pathway of communication for members of the group.

Early on in the study, the participants worked with material based on movements from the *Rite of Spring*, a ballet originally choreographed by Vaslav Nijinsky with music composed by Igor Stravinsky. When it was first performed in the

early 1900's, the music and choreography created great controversy. While classical ballet followed a specific syllabus of shapes and lines, the movement in this ballet strayed from the norm and mirrored the more heavy, grounded, pulsating rhythms seen in Stravinsky's score. As the premise is on pagan rituals, the movements reflect a tribal ritual. In interviews, focus group discussions, and during informal conversations, several participants reflect on this particular term as being an exciting part of the project. The participant described in case study two talks of this particular ballet numerous times throughout her one-to-one interview and this can be seen in quotes included throughout her case study in Chapter Eight. She reflects on the tribal feeling that was embedded within the *Rite of Spring* when talking about how important the sense of group is to her and other dancers.

Our results, both quantitative and qualitative, suggest that the social aspect of the ballet classes and the new friendships built are highly valued and important to participants in this study.

9.9 A Cultural and Educational Experience

While quantitative methods in this PhD did not specifically assess or demonstrate the value of the cultural experience, this theme was drawn from more qualitative discussions with participants. For instance, in case study three seen in Chapter Eight, the participant describes the dancing as being a cultural experience. In focus group discussions this same participant reiterates that he enjoys going to the theatre and watching the live performances together with the group (this was

also discussed in the section above looking at socialization). In a different focus group discussion, the participant described in case study two reflects on the sessions and positively notes that the focus is on the art and not on Parkinson's. This is reflective of English National Ballet's (ENB) aim to provide classes that focus on learning about ballet as an art form rather than how it can be used as a therapeutic tool, even though the research looked at potential therapeutic benefit.

During a focus group discussion the participant described in case study five discusses how he feels dancing in a professional institution adds to the experience. He states that any athlete would like to be in a professional environment and he likens dancing at ENB to playing football at Wembley stadium. For this participant, dancing in a professional environment is exciting for him and as mentioned previously, he feels as though he is part of an "exclusive club."

The latter part of section 9.8 of this chapter described a particular term that focused on choreography from the *Rite of Spring*. When ENB were invited to take up residency in the Tate Britain museum for one week, the participants were invited to carry out their usual Saturday afternoon class in one of the museum halls. In a focus group discussion, the participant described in case study one stated this was probably, for her, the highlight of the whole project. When she made this point, others in the room also nodded their heads in agreement. The participant described in case study two agreed and stated that although she had no particular urge to perform, there was a sense of occasion about it and it was nice to see the audience appreciation.

As discussed above, while participants within the project had an opportunity to perform, they also were able to participate in theatre trips to watch the company perform as well. During casual conversations at the theatre participants noted that they were better able to understand the storylines and appreciate the performance after having learned about the ballet in class and the specific characters involved in the story.

While participants in formal and informal conversations did not explicitly discuss continued education in adulthood, the value of focusing on the art of ballet rather than on the Parkinson's is something that was clearly appreciated by participants. Furthermore, it seems that this educational component of the ballet classes is possibly one way in which this form of activity stands out as being unique from other forms of physical activity and exercise.

In his book entitled, "Adult and Continuing Education", Jarvis (1995) discusses how the elderly have just as much right as anyone else to enjoy the benefits of learning. He describes how leisure-centred education can help people to relate more easily with contemporary culture, can help them to use their time in a creative manner, and can help to enrich the lives of those that take part. Taking the above into consideration it seems that through participation in a cultural activity like ballet, participants can take part in a physical activity that may help to improve or maintain health but that may also provide the benefits of continued education as described above.

Cohen et al. (2006) measured the impact of professionally conducted cultural

programs on physical and mental health as well as social functioning in older adults across a 12-month period. 166 participants (mean age of 80) were divided randomly into an intervention group who took part in choral singing and a control group who continued with their normal activities. Results showed that participants in the intervention group reported higher overall physical health and less medication use when compared to the control group. The intervention group also saw improved morale, less loneliness, a trend towards increased activity that was not seen in the control group. Cohen et al. (2006) have shown that a cultural activity like chorale singing can also help to improve perceived physical health and deal with issues of loneliness and isolation.

Alongside developing the International Classification of Functioning, Disability, and Health, the World Health Organization (WHO) in 2002 developed a policy framework for Active Ageing. The WHO describes active ageing as the process of “optimizing opportunities for health, participation and security in order to enhance quality of life as people age.” In this instance “active” is to refer to participation in social, economic, cultural, spiritual, and civic affairs rather than just the ability to be physically active.

The new framework or paradigm calls for policies and programmes that aim to enhance health (physical, mental, and social), that support learning at all ages and that encourage participation in socioeconomic, cultural, and spiritual activities according to basic human rights, capacities, needs, and preferences (WHO, 2002). Furthermore, the framework states that policies and programmes should address the social, financial and physical security needs and rights of

people as they age. The framework reiterates that ageing takes place within the context of other people including friends, work associates, family, and neighbours. Thus policies and programmes that encourage the factors described above will help to nurture interdependence as well as intergenerational solidarity that are important aspects of active ageing.

With regards to the WHO policy on active ageing it would appear that participation in ballet classes could help to support many of these aims and objectives. While the policy itself goes into great detail and includes various small proposals under the main domains of health, participation, and security, the following explanation will look more broadly at how the ballet classes could be helping to meet the three main aims. While non-motor and motor impairments did not show significant change in the present PhD project, there is reason to believe that this could be due to the low frequency of the sessions and a lack of physiological overload. Research has shown that dance can provide physical and psychological benefit when carried out 2-3 times per week (Hackney and Earhart, 2009a; 2009b; 2010a; 2010b; Batson, 2010; Marchant et al., 2011). The ballet classes were supporting and encouraging learning for a variety of ages as participants learned new motor skills as well as historical and contextual information about the ballet pieces they were performing. The ballet classes were in themselves a means of participating in the community for these individuals however participants were also encouraged to attend other events outside of the studio, such as theatre visits and behind the scenes talks with company staff members. It is interesting to note that both dancing and control participants were able to take part in these events outside of the dance studio and thus participants

in both groups may have gained a certain level of social and emotional benefit from this. While this could be viewed as a potential flaw or limitation to the study, there were not many theatre visits and the control participants did not partake in all events.

The ballet classes also created a kind of social security network provided by the relationships built within the classes. While the classes encourage participants to try new movements on their own, student volunteers are available to help when needed. Volunteers in the classes ranged in age from 18 to 60+. As such, these classes in particular were encouraging a sense of intergenerational solidarity.

The arguments above demonstrate that ballet may be a beneficial activity for the ageing population and certainly people with Parkinson's when considering the aims of the active ageing policy.

9.10 Limitations

As discussed in Chapter Three, I participated in the weekly ballet sessions on a regular basis and talked with the participants before and after class. As such, I was able to gather rich data about the participant experience. However, this meant that it was not a blinded study and I was aware of participants who danced on a weekly basis and participants who were in the control group. Care was taken to apply ID numbers where possible to avoid bias however, the ID numbers needed to be removed when triangulating the quantitative and qualitative data. As discussed in Chapter Three, many of the quantitative measurements did not

allow for much subjective interpretation whereby data from control participants would be treated differently than data from dancing participants. Alvesson and Sköldberg (2009) state that all data and facts are “constructions or results of interpretation: we have to do something with out sensory impressions if these are to be comprehensible and meaningful,” (pp. 1). While all data is the result of some level of subjective interpretation, the present thesis argues that this interpretation spans across all data in a similar fashion within the present study rather than allowing for differing treatment of control and dancing participants. As such, this thesis argues that the lack of a blinded design and the resulting potential bias did not likely impact upon the quantitative results of this particular study. However, the qualitative data was gathered with knowledge of who the people were and how they responded in the ballet class. While one could argue that we cannot know for certain if this affected the results, the researcher made sure to only use direct quotes and ideas from participants in the triangulation of data. The researcher was aware of the potential limitations of attending the ballet classes prior to carrying out the research, and as described above, took appropriate measures to gather rich data about the participant experience while trying to avoid bias that would affect the results.

As discussed previously in this chapter, the knowledge of what the study was trying to assess may have caused a placebo effect for participants in the dancing group as they were aware that they were in an experimental situation. However, this effect does not seem to have affected many of the variables assessed in this PhD study. That said, we could not know for sure if dancing participants in the interviews, focus group discussions, and informal conversations were responding

positively because they were aware of the nature of the study and what we were trying to assess. While there was an awareness of this limitation prior to the onset of the study, it was not possible to influence the participants' awareness of being in either the dancing or control group. However, consideration of the possible placebo affect was taken into account and discussed earlier in this thesis.

A lack of research outlining the potential problems with inertial sensors for people with pacemakers and deep brain stimulation meant that multiple participants were not able to complete the gait assessment (see Appendices 4 and 6 for participant briefing papers). This led to a decreased sample size for the gait assessments. It is unknown what the results would have shown had these participants been able to take part in these assessments and the sample sizes been increased. There is a need for further investigation into these issues.

Across the duration of the study it was clear that the rating scales and questionnaires were presenting a slight problem for some participants. During the rating of the UPDRS motor subscale the research team noticed that at times, participants demonstrated certain actions that were not necessarily included or scored on the rating scale. For instance, participants sometimes kept their thumb in when opening and closing the palm of their hands but the rating scale did not allow for this to be documented or considered. Furthermore, some participants had a tendency to lean or fall back after arising from a chair. Such an action indicates reduced stability but again, the rating scale did not allow for such actions to be accounted for in the scoring. The questionnaires included in the present thesis were standard questionnaires that had been previously validated

and used in multiple studies before the onset of this study. Thus, the questionnaires could not have been modified without a significant amount of work. As such, additional notes were taken by a different member of the research team and written alongside the scoring.

While the administrator is instructed to rate what they see and to avoid trying to determine whether a particular impairment is due to Parkinson's or other conditions, at times participants made it clear that there were other reasons for difficulties with tasks. For instance, conditions such as chronic pain, cellulitis, arthritis, and bone injuries were all recorded alongside components of the UPDRS when the administrator was notified by participants that these issues were likely impeding their ability to carry out specific tasks. The researcher was not aware of these particular limitations prior to the onset of the study. However, measures were taken by the researcher and physiotherapist throughout the study to record relevant issues that were discussed or observed during a participant's testing. These issues were reviewed and considered in the final triangulation of results and in the case studies seen in Chapter Eight. It is possible that the issues discussed above have affected the results from the UPDRS. However, this is not a limitation specific to this thesis study but rather, all studies that utilise this scale. As discussed above, modifying the scale could not have been done without significant amounts of work over a longer period of time.

For some participants questions in part two of the UPDRS were difficult to answer. Some felt that it would be more appropriate to choose a number in between scores and others felt that they had problems with a particular situation

but not in the way that the wording suggested in the questionnaire. Some of the questions within the Activities Specific Balance Confidence (ABC) Scale caused confusion for a few participants as they felt that their answers would differ depending on the situation and environment they were placed in. When participants were unclear about certain questions, they were able to talk to the researcher to gain further clarity before providing the most appropriate answer.

All questionnaires were sent to participants in the post prior to their testing date. Participants were asked to complete the questionnaires before attending their session and any questions or queries would be addressed on that day. While this protocol was necessary to keep the duration of the testing sessions to a reasonable length, this protocol relies on participants (and/or their carers) to fully read the instructions and complete each subscale appropriately. While the researcher tried to catch any missing questions or problems at the data collection points, some questions were missed and in these situations missing data protocols were followed (see Chapter Three, section 3.8). For the ABC scale, although instructions were provided that asked participants to rate their scores on a 100% scale in increments of ten, multiple participants consistently recorded their scores in increments of five. Scores were always rounded down in this situation. Prior to the onset of the study the researcher was aware that missing data was likely to occur at some point throughout the multiple years of data collection. As this limitation was accounted for and dealt with in an appropriate way, the thesis argues that these smaller points did not likely affect the overall picture and results of the study.

Past research has discussed the difficulties and limitations with summing ordinal data often seen in questionnaires and using means and standard deviations to represent change across time or differences between groups. In her article looking at the validity and reliability of using the SF-36 as an outcome measure of physiotherapy, Mawson (1995) states, “The individual items within an ordinal scale should also be unique, however. Once data are summed, the ordinal scale loses its uniqueness,” (pp. 211). In her article Mawson concludes that, “the resultant analysis can be extremely inaccurate and misleading,” (pp. 211). This author is demonstrating how the total scores can essentially be composed of a variety of options and thus each independent item loses its independent value.

Current practice in the dance for Parkinson’s field often uses parametric statistics to analyse questionnaire data when the appropriate assumptions can be applied. While the present study used non-parametric statistical analysis due to a lack of normal distribution, all questionnaire data was still summed and means with their standard deviations were used to discuss changes across time and differences between groups. However, this approach can result in the loss of meaningful change. It would therefore be useful to analyse the data using other non-parametric options that focus on changes to frequency of scores, thus preserving the individual value of each questionnaire item.

9.11 Future Research

Throughout the present thesis recommendations for future research have been made. The aim of this section is to summarise these suggestions and present

arguments explaining why these ideas should be explored further.

The overarching aim of the present thesis and a recommendation that has been made for future research is for a better understanding of how dance may impact people with Parkinson's physically, mentally, emotionally, and socially. Chapter Two argued for the consideration of the World Health Organisation's International Classification of Functioning, Disability, and Health (ICF) as a framework that could help researchers to meet this aim. The ICF considers not only the physical or mental impairments that people may suffer with but also how they can still be active participants in society and maintain a positive life despite those impairments. As this particular framework is familiar and utilized across a wide range of fields, its application to this field of research will be useful in disseminating important findings to a wider audience and those working with Parkinson's patients. Chapter Eight of the present thesis evidences the significance of considering personal and environmental contextual factors when discussing research findings. For instance, one case study discussed how a dancing participant also attended the gym on a daily basis and carried out exercises that she felt were improving her ability to rotate in the torso. While the present study was not able to discern between the gym-based activity and the dance-based activity with regards to axial rotation, it is important to account for this when looking at this individual's results. Furthermore, a participant who lost his partner to cancer near the end of the study also saw a decrease in his certainty about maintaining positive aspects of his life in the future. Again, the present study did not aim to determine the reasons for particular results. The drop in this participant's score may not have been related to his recent loss. However, it is an

important personal contextual factor to consider when comparing his result to the majority of dancing participants who saw improvement in this area. The use of the ICF proved useful in the present thesis and thus future research should consider this framework when trying to assess the impact dance may have on this population. With regards to personal and environmental contextual factors, case studies may present an ideal way to consider these elements in relation to the wider results. However, as discussed in Chapters Six and Nine, caution should be taken when trying to apply the ICF to existing assessments and rating scales that do not aim to consider this particular framework. In these cases, researchers should be explicit about how and why certain assessments or subscales represent domains within the ICF. If there are multiple domains represented within a particular subscale researchers need to clearly explain if and how they continued to apply the framework.

A mixed methods approach allowed for a better understanding of how experiences both inside and outside of the dance studio were affecting change. Through biomechanical assessments of gait, multiple participant questionnaires, a clinical rating scale, interviews, group discussions, and informal conversations, this study assessed the value of the dancing experience for participants from multiple different angles. The range of assessments allowed for interesting discussions about the differences between participants' perceptions of change and the measured change in this study. Furthermore, the range of assessments encouraged discussion about changes at various levels of the ICF framework. While aspects of quality of life can be assessed through a range of quantitative assessments, talking with participants and understanding what is most important

and meaningful to them can provide insight into the full value of dance for this group of people. By taking a view that there are multiple ways of analysing how the dancing experience may affect change, this study was able to draw out some key features of the dance classes that were meaningful to participants. While the weekly ballet sessions did not show significant physical change, interviews, informal conversations, and questionnaires demonstrated that participants did not necessarily attend the sessions purely for physical gain. Rather other social and emotional benefits encouraged continued participation in the classes and were often the aspects that were discussed more readily in interviews and group discussions. Future research should consider the potential benefits of a mixed methods study but also the limitations of spreading resources and focus across multiple different assessments. The chosen approach should be one that best represents and answers the research questions posed.

Throughout this thesis recommendations have been made for future research to look at the mechanisms within a dance class that are responsible for physical change. While recent research has shown that participation in dance may help to improve balance, gait, and functional mobility for people with Parkinson's, there is still a lack of knowledge with regards to which movements elicit positive change. Without this understanding, dance programmes may not be including the most physically beneficial activities. Connected to this issue is the lack of research looking at which form of dance provides the most benefit for this group of people. Furthermore, this thesis argues strongly for clearer guidelines regarding the optimal frequency and intensity for dance programmes. Recent research has often shown significant physical improvement with a dance class

frequency of at least 2-3 classes per week. The present study found no significant physical improvement with a weekly ballet session across 12 months. It is unknown what the result would be if the ballet class frequency was increased or if modifications were provided to allow increased intensity for certain individuals. Future research should focus on gaining an understanding of best practices within dance for Parkinson's programmes.

Chapters Four and Nine brought forth arguments suggesting that future research should look to vary methods of assessment, especially when studying changes to balance. While the present thesis recognizes that rating scales commonly used to assess balance in dance for Parkinson's research have been deemed valid and reliable, these scales do not necessarily distinguish between static and dynamic balance. The chosen assessments within this study looked specifically at dynamic stability or balance during walking. As assessments of static balance may not be comparable to assessments of dynamic balance and balance in locomotion is an important indicator of fall risk, future research should look to assess this variable.

Recent research including the present thesis has argued for longer duration studies with larger sample sizes. Most studies to date have looked at shorter durations between 3-6 months. While some studies have looked at longer durations between 10-12 months, few studies have achieved this length. There are variety of reasons why a longer duration study may not be possible including feasibility issues such as a lack of space, finances, and general resources. Furthermore, it may be difficult for participants to continue participating over a

longer period of time as their condition progresses. However, findings from the present study suggest that an understanding of longer-term effects as a result of dance-based activity is essential. As discussed earlier, dancing participants who volunteered for the research had already been taking part in an existing ballet class at English National Ballet studios. All participants included in the research had been dancing for at least 3 months prior to baseline measurement while the majority of participants had been dancing for over one year prior to baseline. To the author's knowledge this is one of very few studies to include participants who had all been dancing prior to the onset of the research testing. It is unclear whether results from the present study are reflecting the fact that participants had already been participating in this ballet programme for quite some time prior to onset of testing. As discussed in Chapter Nine, if levels of overload and progression are not strong enough to elicit physiological change, participants may find that they plateau at a certain level. Future research should look at longer-term benefits and aim to address the principle of overload to avoid physiological plateau.

As it may not be feasible for participants to take part in an organised dance class multiple times per week over a longer period of time, future research should look at self-management techniques that could be used alongside set classes. David Leventhal and the team at *Dance for PD*® in New York have developed three volumes of DVD's that help people with Parkinson's to continue practising elements of the dance class in the comfort of their own home. Additionally, the 'Moving Through Glass,' project created by Mark Morris Dance Group in conjunction with the creative agency SS+K and Google, have developed an

portable device that allows people with Parkinson's to experience elements of the dance class anywhere and at any time. The portable device resembles a pair of glasses with video projections of dance movements displayed in the corners of the lenses, allowing wearers to move freely while following the movement instructions. Researchers from New York Presbyterian/Weill-Cornell Medical Center and Stanford University's Movement Disorders Center are working to refine the software and explore new stages of development (Dance for PD, 2010-2015). The home-based DVD series and the 'Moving Through Glass' project are examples of how one might be able to implement daily practice of dance movement in a feasible way. However, further research is needed to understand the potential benefits of these self-management programmes in relation to existing dance for Parkinson's research. It seems that while these programmes may be useful with regards to body function, they may not be as useful in providing the level of social support and sense of community that was so valued by participants in the present study.

Research by Mawson et al. (2014) and Parker et al. (2014) discuss the development of a personalised self-management system for post stroke rehabilitation. Through multiple articles these authors investigate the key elements required for the development and utilisation of an interactive, home-based system that helps individuals who have suffered a stroke improve and achieve individual life goals. The mechanisms of the system are underpinned by theories of motor relearning, neuroplasticity, self-management, and behaviour change (Mawson et al., 2014). With regards to future research in the dance for Parkinson's field, the work carried out by Mawson et al. (2014) may help

researchers to refine and develop systems that aim to provide individual's with immediate feedback about their movement, thereby enhancing self-efficacy and potentially quality of life.

In connection to the above thoughts, there is a need to further investigate the relationship between music and movement in the context of dance for people with Parkinson's. While numerous studies have evidenced the connection between rhythmic auditory cueing and improved fluency in movement for people with Parkinson's, there is a lack of research that addresses how long these benefits last. Chapter Nine discusses how participants, instructors, and observers of the ballet classes often commented on the improved gait patterns seen when participants walked to a strong rhythm. While anecdotal comments and observations demonstrated that these improved gait patterns lasted for a short period after the ballet classes had finished, quantitative results demonstrated a lack of significant change across the duration of the study. When testing, participants were not walking to music and had not been dancing immediately prior to their testing session. Thus, for the present study it appears that the beneficial effects of music on gait patterns did not continue outside of the dance context for these participants. However, it would be beneficial for future research to more closely examine this relationship and compare gait patterns when participants walk to music with walking on a non-dancing day without music.

Further investigation is also needed with regards to the role that axial rigidity and a decreased range of motion play in trunk coordination patterns. Previous studies have shown that people with Parkinson's tend to move the pelvis and thorax in a

more in-phase pattern in comparison to the more anti-phase pattern seen in healthy controls. Findings from the present study are in accordance with previous research and demonstrated that participants were generally moving in a more in-phase pattern and this did not significantly change across the 12-months (see Chapter Five for further details). Upon critically analysing the results questions arose about whether the participants were walking quickly enough to assume an anti-phase coordination pattern. Previous research suggests that as walking speed increases the torso moves from a more in-phase to anti-phase pattern. However, those with Parkinson's tend to walk slower and this can be a result of increased axial rigidity making it more difficult for people to efficiently oppose movements in the trunk and pelvis in motion. Future research is needed to understand better the relationships between trunk coordination, walking velocity, and axial rigidity during gait. It could be that people with Parkinson's are moving the trunk in a more in-phase pattern to account for axial rigidity and the subsequent decreased walking speed.

Lastly, detailed discussions throughout this thesis have addressed why the lead researcher decided to avoid interference with participant medication plans. Due to the high variability as well as the lack of significant change seen within the present study when medications were not controlled for, there is question of how applicable results from previous studies are when participants are in a different state to when they were tested. If participants are always measured in an "On" state, clarity is needed for what this means with regards to functioning when participants are in an "Off" state. As Parkinson's is such a variable condition with symptoms fluctuating day-to-day and week-to-week, it appears necessary to

understand how dance may benefit people with Parkinson's at all stages or levels of their present condition.

9.12 Chapter Summary

This chapter outlined some of the key findings from the present thesis and discussed in further detail how these issues relate to the wider dance for Parkinson's field. The limitations and aspects of the study needing further consideration were discussed and suggestions for future research were made.

The lack of significant change in physical impairments led to some important conclusions. First, there is a need for future research to vary methods of assessment, particularly in the case of balance measures. While commonly used clinical rating scales have shown to be valid and reliable methods of balance assessment, these scales do not distinguish between static and dynamic balance and may be biasing our understanding of the how dance affects this variable. Secondly, there is a need to understand more about the mechanisms of change and optimal guidelines for the frequency, intensity, duration, and type of dance-based activity. This is especially true given the numerous studies that have evidenced significant positive improvement after a dance intervention for people with Parkinson's. Without an understanding of which movements are eliciting positive physiological change or guidelines for best dance practice, people with Parkinson's may not be benefiting as much as possible from dance-based activity.

Upon reviewing the movement material it was clear that many of the ballet exercises fulfilled recommendations made by Keus et al. (2007) and Ramaswamy and Webber (Parkinson's Disease Society, 2008a) for best practice with regards to physical activity for people with Parkinson's. However, there is still a lack of research in the field evidencing how these exercises or movements are directly linked to changes in physical fitness components, though many articles have postulated that certain movements or exercises will improve these fitness components. Specifically, there is a lack of research evidencing how movements carried out in a ballet class are directly linked to significant changes in physical fitness components.

Guidelines set by The Centre for Disease Control and Prevention (CDC) state that people should be carrying out at least 150 minutes of exercise per week. The present study looked only at once weekly ballet classes and also worked with participants who had already been dancing for at least three to four months prior to baseline measurement, if not longer. It is unknown what the results would be with an increased class frequency and an appropriate amount of physiological overload applied to all participants across the 12 months.

The present study found significant positive correlations between measures of physical impairment and measures of difficulties with everyday activities. This particular finding is important considering the arguments made throughout the thesis stating the need for understanding how changes to impairments impact upon daily activities and participation in society. While there appeared to be a significant positive relationship between impairments and activities of daily

living for this group of people, it is difficult to interpret these results given the lack of significant change in both areas across the duration of the study. However, this finding suggests that physical impairments do impact upon activities of daily living for people with Parkinson's.

The mixed methods approach to this work uncovered some interesting discrepancies between participants' perceptions of physical change and the measured physical change. It was also interesting to note that although there was a general sense that the dancing was doing some good, participants found it difficult to verbalise exactly how or what was changing for the better as a result of the ballet classes. However, some of the results from the dance for Parkinson's questionnaire as well as qualitative data gathered through interviews, group discussions, and informal conversations evidenced that the dancing was offering other social and emotional benefits that were valued and important to the participants involved. Although insignificant the dancing group saw improvements in their certainty about maintaining positive aspects of future life. This result was not seen in the control group. Furthermore, the dancing group felt that their illness was not interfering with their life as heavily by the end of the project while the control group felt it was interfering more. Again, these results were insignificant but the contrast between the groups is worth mentioning, especially considering participant comments in interviews and group discussions. Case study analysis in Chapter Eight demonstrated that participants valued the social interaction. Some felt that the social nature of the classes acted as a support mechanism that encouraged participants to try new things and others discussed how it was nice to feel wanted and as though others were happy to see

them. Participants suggested that the social interaction along with the live music were reasons why they enjoyed the sessions and why they were motivated to keep attending the classes. Participant comments reflected findings from previous studies demonstrating that the auditory, rhythmic cueing present in the music was helping participants to move with more fluency and control. However, it is unclear how long the physical benefits achieved from this rhythmic cueing lasted for participants outside of the dance context. Further investigation would help researchers to understand how best to extend the physical benefits gained from moving to music for people with Parkinson's.

When asked if participants felt that dancing provided anything different from other physical activities the social nature of the classes and the live music were again discussed in detail. One participant even mentions that moving to music unites the body, the mind, and the soul. Additionally the cultural aspect of the sessions and the fact that participants were learning new things about this particular art form allowed participants to feel as though they were taking part in an enriching experience while also remaining physically active. These aspects were what participants felt made the ballet experience unique in comparison to other physical activities. While most studies in the field have focused on how dance, in a variety of forms, may benefit people physically, the present thesis has shown that even when physical impairments have not significantly changed for the better, participation in ballet is still valued for other psychological, social, and emotional reasons. These other benefits may positively influence quality of life and thus participation in other life situations.

The use of the International Classification of Functioning, Disability, and Health (ICF) as a framework proved useful for the present thesis in understanding how dance might benefit this group of people physically, mentally, emotionally, and socially. However, researchers should take caution when trying to apply the ICF framework to existing scales that were not created with the ICF model in mind. Depending on the chosen methods it may be difficult to categorize certain assessments into the appropriate ICF domain. In these cases authors need to be explicit about how and why various assessments have been allocated into a particular domain within the framework. Future research should continue to think about the ICF domains and should further assess which elements of the dancing experience are most valued and important to participants.

Chapter Ten

Conclusion

The beginning of Chapter Three outlined the four main research aims and four research questions that this thesis aimed to address. To review these aims and questions are as follows:

Research Aims:

1. To employ a mixed methods approach to study the physical, mental, social, and emotional effects of dance on people with Parkinson's
2. To engage with and advocate for an internationally recognized framework that can be employed in future dance for Parkinson's research using findings from this mixed methods study
3. To better understand what dance can provide for people with Parkinson's that is similar or different to other physical activity forms
4. To determine relationships between variables being assessed to better understand the impact that dance can have on this population

Research Questions:

1. Does participation in a weekly ballet class help people with Parkinson's cope better with their motor and non-motor symptoms?
2. Does participation in a weekly ballet class help people with Parkinson's carry out activities of daily living with more ease and efficiency?
3. Does participation in a weekly ballet class for people with Parkinson's influence their levels of participation in the community and in society?

4. Does participation in dance offer additional benefits that may not be seen in other physical activity forms for people with Parkinson's?

With regards to the first research question, participants in both dancing and control groups demonstrated no significant changes with regards to motor and non-motor impairments across the study. However, the results from the dance for Parkinson's questionnaire pose interesting questions with regards to the participants' ability to cope better with their condition. Although insignificant the strong improvement in illness interference scores suggests that participants in the dancing group were possibly finding ways to cope better with their condition despite their physical and mental impairments. However, further investigation is needed to substantiate these arguments given the insignificant results. The social nature of the classes and the focus on ballet as an art form rather than as a therapy helped participants to stay physically active in a fun, positive way. While the present study did not find any significant physiological improvement from the weekly classes, it could be argued that the social support and active learning helped participants to cope better with their condition, despite their symptoms. Furthermore, qualitative data and movement observations suggest that the rhythmic auditory cueing inherent within the musical accompaniment helped participants to move in a more fluid and coordinated manner. While these observations happened specifically in the dance classes, participants anecdotally commented on how they would often hum a tune to help with walking and movement outside of the dance context.

With regards to the second research question, the present study did not find any

significant changes with regards to activities of daily living after 12 months of weekly ballet classes. However, Chapters Six and Seven evidenced significant positive correlations between measures of motor impairment and measures of difficulties with everyday activities. These findings suggest that as physical impairments progress, participants across dancing and control groups experience more difficulties with everyday tasks and as impairments improve, so do activities of daily living. As there were no significant changes in either dancing or control group for measures of everyday activities or for physical impairments, it is difficult to interpret exactly what this positive correlation means for this group of people. However, the connection made here warrants further investigation and future research should concern itself with how impairments or changes to impairments are impacting upon activities of daily living outside of the dance class.

The present thesis looked at the domain of participation with reference to previous research connecting improved quality of life with improved participation in activities. It has been suggested that future research should aim to understand the facets of activity participation and what changes may influence individuals to participate more in life situations. Thus, rather than directly assessing changes to activity participation, this thesis aimed to look at changes to aspects of quality of life that could impact upon participation in society. Although no statistically significant changes were found with regards to aspects of quality of life measured in the Dance for Parkinson's questionnaire, qualitative data suggests that there were psychological, emotional, and social benefits gained from participation in the weekly ballet classes. Participants noted

the value in learning about something new and finding appreciation for an art form that they may not have learnt about otherwise. Furthermore, the social interaction and support was both meaningful to participants and a key motivator to continue attending the sessions each week. Interviews and discussion groups also found that participants were interacting with each other outside of the dance class context in their own time. Through participating in the ballet classes participants gained valuable experiences that might encourage participation in other activities that provide similar social and intellectual benefit. The music was often regarded as being an important part of the dancing experience and helped participants to move with more ease and fluidity. As moving to music was a pleasurable experience for so many, it may encourage further participation in dance-related activity in the future.

Connected to the above thoughts, participants noted that the music, the social interaction, and the cultural experiences added to their enjoyment of the ballet classes and made the experience enriching and unique. Furthermore, participants enjoyed being around others with Parkinson's but participating in a physical activity that did not focus on the limitations of their condition. For the dancing participants, these elements made the dancing experience unique in comparison to other physical activities that they had taken part in or had been encouraged to do. While the weekly ballet classes did not offer significant physiological benefit, the classes did offer equally important benefits that were valued and meaningful to the participants involved. For many, the classes have become an important part of their weekly routine and encouraged additional interactions outside of the context of the study.

Interviews, focus group discussions, and conversations with participants suggested they believed the dancing was doing them some good. The present thesis has found that the ballet classes were doing them good in a variety of different ways. While significant physiological benefit was not demonstrated, this does not mean that all individuals did not see clinically meaningful improvement. Furthermore, many participants demonstrated clear improvement in the dance classes themselves. Further investigation may be able to determine if increased class frequency and additional physiological overload may lead to a different statistical result. However, the present thesis has found that the stronger benefits and the elements that were more readily discussed in interviews and focus group discussions were based around the nature of the classes and the social support gained from participation in those classes. The pleasurable emotions experienced in the sessions, the joy of moving to music, being active and communicating with other Parkinson's people, and continuing to learn new things were all important components that encouraged participants to keep dancing.

Appendix 1: Glossary of Clinical Scales and Tests

In the order that they present within the thesis:

Functional Axial Rotation: assesses how far an individual can rotate the torso around the spine while maintaining pelvic stability

Functional Reach: assesses how far an individual can reach to grasp an object in front of them at a certain distance away without losing balance

Gait Speed or Walking Velocity: refers to how fast an individual is walking

Cadence: refers to the number of steps completed per second during gait

Six-Minute Walk Distance (6MWD): assesses how much distance an individual can cover when walking for 6 minutes.

Stride length: a measure of the distance between when the heel of one foot strikes the floor during a walk and the next moment that same heel strikes the floor again. This can be measured in the forward or backward direction.

Single support time: refers to the time spent supporting the weight of the body on one leg as the other leg swings through during gait.

Tandem stance: refers to a test of balance where participants need to stand for a period of time with the heel of one foot directly in front of the toes of the other so that they are said to be “in tandem”.

The Semi-tandem test: this measure asks subjects to stand for 15s with one foot behind the other so that the big toe of one foot is touching the side of the heel of the other.

The Timed Up and Go (TUG): assess how quickly an individual can rise from a chair, walk 3-meters, turnaround, walk back to the chair, and sit down.

The Sit to Stand test: often carried out over a set period of time, this test asks participants to stand up from a chair without using the arms of a chair (sometimes multiple times) to assess functional lower extremity strength

The Fullerton Advanced Balance (FAB) scale: this scale consists of 10 tasks that challenge participants’ ability to balance in both static and dynamic situations.

Appendix 2: ENB Company Repertoire

1. Sleeping Beauty
2. Ecstasy and Death
3. A Tribute to Nureyev
4. Le Corsaire
5. Lest We Forget
6. Coppelia
7. Modern Masters
8. Swan Lake

Appendix 3: The Dance for Parkinson's Questionnaire

Reference number/name: _____

The McRae Dance for Parkinson's Questionnaire (Follow up)

Thank you for agreeing to complete this questionnaire as part of Roehampton University's research for English National Ballet's *Dance for Parkinson's* programme. If you would prefer not to answer a question, please leave it blank. All answers will be anonymised and your identity protected on publication.

We would like to ask some questions about how you are managing with Parkinson's. Please read each question carefully. There are no right or wrong answers and your first thought is usually the best.

In general, how would you describe your health at the present moment? (Tick one)

☐ Excellent ☐ Very Good ☐ Good ☐ Fair ☐ Poor

We know there is often a lot of fluctuation in Parkinson's. We are interested in how well you can perform the following daily activities AT YOUR WORST? (Tick one for each row)

	Normal	Adequate	Limited	Need Help	Unable To Do
Walking.....	_____	_____	_____	_____	_____
Dressing.....	_____	_____	_____	_____	_____
Eating.....	_____	_____	_____	_____	_____
Bathing.....	_____	_____	_____	_____	_____
Grooming.....	_____	_____	_____	_____	_____
Getting up from chair _____	_____	_____	_____	_____	_____
Turning in bed...	_____	_____	_____	_____	_____
Writing.....	_____	_____	_____	_____	_____
Talking.....	_____	_____	_____	_____	_____
Fine motor.....	_____	_____	_____	_____	_____

Talking..... _____ _____ _____ _____ _____

Fine motor..... _____ _____ _____ _____ _____

Please rate the severity of each of the following problems AT YOUR WORST. (Tick one for each row)

	None	Mild	Moderate	Severe	Very Severe
Tremor.....	_____	_____	_____	_____	_____
Stiffness.....	_____	_____	_____	_____	_____
Slowness of movement.....	_____	_____	_____	_____	_____
Freezing when walking.....	_____	_____	_____	_____	_____
Falling.....	_____	_____	_____	_____	_____
Imbalance.....	_____	_____	_____	_____	_____
Problems with Gait.....	_____	_____	_____	_____	_____
Stooped Posture.....	_____	_____	_____	_____	_____
Lack of Flexibility.....	_____	_____	_____	_____	_____
Pain.....	_____	_____	_____	_____	_____
Dyskinesia (excessive movement).....	_____	_____	_____	_____	_____

Overall, how free or restricted do you feel in doing what you want to do? (tick or circle the appropriate number).

**I can still do everything
I want to do**

**I can no longer do the things
I want to do**

1 2 3 4 5 6 7

Using the scale below, please indicate which number best describes the present stage of your Parkinson's: _____

0 = No signs of Parkinson's.

1 = Evidence of Parkinson's on one side of the body.

2 = Evidence of Parkinson's on both sides of the body (bilateral), without impairment of balance.

3 = Mild to moderate bilateral symptoms; some postural instability; physically independent.

4 = Severe disability; still able to walk or stand unassisted.

5 = Wheelchair bound.

Please indicate your level of certainty about the following items.

How certain are you that you can:

Make some positive changes in your life?	1	2	3	4	5	6	7
Have hope for the future?	1	2	3	4	5	6	7
Enjoy learning new things?	1	2	3	4	5	6	7
Have a sense of achievement?	1	2	3	4	5	6	7
Develop more confidence?	1	2	3	4	5	6	7
Manage your situation so you can continue to do the things you enjoy?	1	2	3	4	5	6	7
Have fun and make new friends?	1	2	3	4	5	6	7
Develop a sense of community with others with Parkinson's?	1	2	3	4	5	6	7

Below is a list of ways you might have felt or acted during the past week. Please indicate how often you felt or acted the way each statement suggests by using the following scale:

Rarely or none of the time (Less than 1 day)
 Some or a little of the time (1-2 days)
 Occasionally or a moderate amount of time (3-4 days)
 Most all of the time (5-7 days)

1. I felt depressed.	_____	_____	_____	_____
2. I enjoyed life.	_____	_____	_____	_____
3. I felt sad.	_____	_____	_____	_____
4. I felt happy	_____	_____	_____	_____
5. I felt lonely	_____	_____	_____	_____
6. I felt motivated	_____	_____	_____	_____

Using the scale below, mark or circle the number that expresses how much you feel your Parkinson's interferes with the following aspects of your life.

My illness interferes with my...

	<u>Very Little</u>					<u>A Great Deal</u>	
Ability to Express My Personality	1	2	3	4	5	6	7
Personal Relationships	1	2	3	4	5	6	7
Sense of Well-being	1	2	3	4	5	6	7
Plans for the Future	1	2	3	4	5	6	7
Sense of Independence	1	2	3	4	5	6	7
Self-Esteem	1	2	3	4	5	6	7
Ability to work or contribute	1	2	3	4	5	6	7

My quality of life at present is: (*Tick one*)

☐ Excellent ☐ Very Good ☐ Good ☐ Fair ☐ Poor

Please indicate how much you agree or disagree with each item by marking the appropriate number. (check or circle one answer for each item)

1 = Strongly Disagree 2 = Disagree 3 = Not Sure 4 = Agree 5 = Strongly Agree

- | | | | | | |
|---|---|---|---|---|---|
| 1. Dancing makes me feel more energetic | 1 | 2 | 3 | 4 | 5 |
| 2. Dancing is mentally demanding and stressful | 1 | 2 | 3 | 4 | 5 |
| 3. Dancing improves my balance | 1 | 2 | 3 | 4 | 5 |
| 4. Dancing is nourishment for the soul | 1 | 2 | 3 | 4 | 5 |
| 5. Dancing increases my negative mood | 1 | 2 | 3 | 4 | 5 |
| 6. Dancing improves my activity tolerance/endurance | 1 | 2 | 3 | 4 | 5 |
| 7. Dancing does not motivate me to be more active | 1 | 2 | 3 | 4 | 5 |
| 8. Dancing gives me a great feeling of togetherness | 1 | 2 | 3 | 4 | 5 |
| 9. The prescribed movements are difficult to perform | 1 | 2 | 3 | 4 | 5 |
| 10. Dancing increases my self-confidence | 1 | 2 | 3 | 4 | 5 |
| 11. Dancing seldom improves my body coordination | 1 | 2 | 3 | 4 | 5 |
| 12. Dancing helps me to feel more in control of my life | 1 | 2 | 3 | 4 | 5 |
| 13. Dancing increases my sense of isolation | 1 | 2 | 3 | 4 | 5 |
| 14. Being with others with PD encourages me | 1 | 2 | 3 | 4 | 5 |
| 15. Dancing makes me happy/brings me joy | 1 | 2 | 3 | 4 | 5 |
| 16. When I dance, I feel more alive | 1 | 2 | 3 | 4 | 5 |
| 17. The class is good exercise | 1 | 2 | 3 | 4 | 5 |
| 18. Greater awareness of my body helps
me in everyday situations | 1 | 2 | 3 | 4 | 5 |
| 19. Dancing takes me out of myself | 1 | 2 | 3 | 4 | 5 |

Thank you very much for responding to this questionnaire! Please use the remaining space to describe any positive or negative aspects of your experience with Dance for PD.

Appendix 4: Research Briefing Paper for Dancing Participants



English National Ballet *Dance for Parkinson's*: An Investigative Study Part 2

Research Briefing Paper (London class)

Dr. Sara Houston and Ashley McGill, Department of Dance at University of Roehampton, will be carrying out a second phase of research from Easter 2012 until summer 2014 following their successful pilot study with English National Ballet in 2010 - 2011. We are delighted that Ashley will be conducting the research for her PhD submission, in collaboration with Professor Raymond Lee, Department of Life Sciences, University of Roehampton.

Many of you will have already spoken to Sara as part of her evaluation of the project. This research is much bigger than the evaluation, with many more areas that will be addressed. For those of you who were there at the introductory session in October, you will know a little about what we intend to do. The aims of the research are:

- To look at the social value of dancing, particularly in whether some kind of community begins to be formed
- To look at whether dancing has any impact in the way you see yourself and what you can do
- To see whether your stability, muscular tension, posture and general health and well being changes with dancing. (A control group, a group of people with Parkinson's who do not dance, will also be taking part in this section of the study).

The research divides into four parts:

1. Interviews and diaries: getting you to talk about yourself and your dancing experience
2. Physical measurement: simple tasks outside of the dance class to measure stability, posture, muscular tension, Parkinson's progression, general health
3. Questionnaires: these will given for you to rate your confidence in balance and your perception of your physical capabilities and well being.

4. Observation: Sara and Ashley take part in the dance class to look at how you are developing as dancers and to help them there will be two extremely small cameras to record those sessions. They will also observe the sociability of the class.

Your participation in the research is warmly welcomed, but if you feel you'd rather not take part in something, even if you said yes at the beginning, you do not have to. You may withdraw at any time. If you don't take part in the research, you may still take part in the dance class.

After we have collected and analysed the data over the 2 and a half years, we intend to publish the results and our thoughts in academic journals and in a book.

Physical Measurements

We would like to carry out some physical measurements focusing on stability, rigidity, posture and general health and well-being. The aim of this research is to determine if dance as a form of physical activity is helping you to cope better with some of the Parkinson symptoms.

In order to take part in the physical measurements you should:

- not have any current injury to the back, or have had recent surgery that would affect the movement of the back.
- be diagnosed with Parkinson's
- be able to walk, or attempt to walk, without an aid, or feel reasonably confident that you can attempt the following measurements with support from other helpers if necessary.
- be aged 55 or over
- be able to communicate effectively, with no signs of dementia
- be aware that the postural and rigidity measurements involve an electromagnetic tracking device. This note is important to anybody who has an electronic implant (e.g. pacemaker or deep brain stimulator). To the best of our knowledge and according to the information provided by the manufacturer, the electromagnetic tracking device that will be used to measure rigidity and posture should not have any adverse effects on any cardiovascular implant (e.g. pacemaker). Please ask the investigators if you have any questions and you should be aware of any potential risk, no matter how matter how negligible it is. Regarding deep brain stimulators, it is strongly advised that you discuss this study with your doctor before consenting to take part in the physical measurements.
- Tell us if you are allergic to sticking plaster.

All of the measurements can be done either at English National Ballet, or at University of Roehampton Dance Department (transport provided) and 1 testing session should take no more than 1.5hrs to complete. Our aim is to do approximately 3 testing sessions per year.

Below is a list of the measurements that Ashley will be co-ordinating and what would be required from you as a participant.

1) Posture

For this measurement I will ask you to wear a shirt that I will provide you with that has a slit in the back so that I can look at your spine. I will need you to stand as naturally as possible as I trace a small sensor up and down your spine. In order to do this accurately I will need to feel your back and sense where certain parts of the spine are before I place the sensors on you. A physiotherapist will help me to identify specific points along your spine and we will place small stickers on these points for accurate measurement.

I will also need to take a quick picture of you standing from the front view and from the side view.

2) Gait and Stability

For this measurement I will ask you to walk for approximately 10-15 steps and then turn around and go back the other way. This will need to be done about 3 times over. Before this walk I will need to attach 6 sensors to you (2 on the back, 2 on the left arm, and 2 on the right arm). All sensors are non-invasive and should cause no pain or discomfort. They will be attached with the use of double-sided tape and it is essential that you make the researchers aware of any allergic reactions to tape that you may have suffered previously. In order to do this I will ask you to wear a shirt that I will provide you with that has a slit in the back. This is so I can see your spine and feel where I am placing the sensors.

Please come wearing a top and trousers/skirt and, if possible, please wear trousers or a skirt with an elasticated waistband, which is easy to move slightly to accommodate the sensor. I will need to be in contact with this part of your back in order to secure the sensor. If you realize you don't feel comfortable with this, please feel free to talk with Sara or myself about ways that will help you feel more comfortable.

In order to carry out the necessary calculations during data analysis, researcher (Ashley) will need to take a basic height and weight measurement before placing the sensors on your back and arms. If you do not feel comfortable with the weight and height

measurements and do not want to have these taken, you can still take part in all other aspects of the research

In addition, we would like to go through the Unified Parkinson's Disease Rating Scale with you. You will all probably be familiar with this if you have seen a consultant neurologist.

3) Unified Parkinson's Disease Rating Scale (UPDRS)

The UPDRS is used by physicians to assess your Hoehn and Yahr score and looks at a variety of things including mental and physical health, ease of carrying out everyday activities, and further questions looking at stiffness, posture, and coordination. Some parts of the scale are looked at through a questionnaire and for other components you will be asked to try out a few small motor tasks.

4) Mini-Mental State Exam

This short test (approximately 5 minutes in length) has been used in previous research to assess cognitive and mental functioning.

You will be asked some questions by a physiotherapist. Questions will focus on things like naming objects in the room and spelling a common word backwards.

Interviews and Diaries

Interviews are usually recorded using a digital voice recorder and notes are taken by the researcher.

1) Interviews in conjunction with the physical testing

Ashley would like to carry out some short interviews with each of you about your thoughts on how the dance classes are helping you physically cope with your Parkinson's.

2) Interviews separate from the physical testing

Sara would like to listen to you talking about yourselves, your experience of dancing and your social activities. These interviews will take place at a time convenient to yourself and Sara and will either take place at Markova House in one of the offices, or if it is more convenient, Sara will visit you at home. These interviews last approximately 20 – 45 minutes, depending on how long you want to chat for. Interviews will happen approximately 2 – 3 times a year.

3) Diaries

The diary is a really useful document to examine what you do in your everyday life, how you are managing your Parkinson's, what your social life is like, how you are feeling and how you are talking about dance. Often people say different things in the diary that they forget to say at interview. If you would like to keep a diary, you may write as much or as little as you want. You may type it, send it by email, hand write something, jot notes on another diary you perhaps keep for a Parkinson's Nurse, you may record it. Everything is useful! You may keep it weekly, monthly or every so often when you remember. Please talk to Sara for more details.

Questionnaires

1) Balance confidence

Balance confidence plays a huge role in how stable we feel on any given day. We would like to look at your balance confidence using the Activities-specific Balance Confidence scale. This scale has 16 items in a questionnaire format that ask you to answer how confident you feel about your stability in various different situations (ie. Walking up/down stairs or picking up something off of the floor). You will be asked to fill in the balance confidence questionnaire when you take part in the physical measurements. If you do not want to take part in the physical measurements, but would like to do this questionnaire, please tell Ashley or Sara and we will arrange a time to do it with you.

2) The McRae Questionnaire

This is a questionnaire which is being given out to dance participants who have Parkinson's in Denver USA. Dr. Cynthia McRae, who devised this questionnaire specifically for people with Parkinson's who dance, has kindly given us permission to use the questionnaire with you. It looks at your perception of your physical capabilities and emotional well being, as well as your perceptions of the dance class. You will fill this in at the beginning of the research and then again on a yearly basis.

Observation

Sessions will be filmed in order to more accurately analyse how you are developing physical skills and to document your creative journey. If you do not want to take part in the filming, then we will omit you from the analysis. Parts of the film may be shown occasionally at conferences or

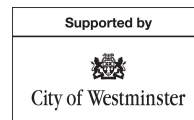
at our University to educate our students. If you do not want to take part in the filming, we will make sure that you are not seen in any of the extracts used.

If you have any further questions about these measurements please do not hesitate to contact Sara or Ashley or talk to us in class. Our email addresses are: sara.houston@roehampton.ac.uk and Ashley.McGill@roehampton.ac.uk

Principal Investigator Contact Details:

Dr. Sara Houston
Dance Department
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Appendix 5: Research Consent Form for Dancing Participants



ETHICS COMMITTEE

PARTICIPANT CONSENT FORM (London dance participants)

Title of Research Project:

English National Ballet *Dance for Parkinson's*: An Investigative Study Part 2

Brief Description of Research Project:

Dr. Sara Houston and Ashley McGill from University of Roehampton will be carrying out a second phase of research from Easter 2012 until summer 2014 following their successful pilot study with English National Ballet in 2010 - 2011. They will be collaborating with Professor Raymond Lee, Department of Life Sciences, University of Roehampton. The research will be looking at the participant experience and value of dancing and on whether dancing makes any difference to stability, posture, muscular tension, Parkinson's progression and general health and well being. Please see the Research Briefing Paper for detailed information.

Interviews will be conducted in a private room either at English National Ballet or in your own home for approximately 20 – 40 minutes. The interviews will be voice recorded. The physical measurements will be carried out at University of Roehampton Dance Department (transport provided) or at English National Ballet in the ground floor studio. Questionnaires will also be given to you either at the physical testing day or after a dancing class.

For the physical measurements you will be asked to carry out a simple walking task and stand as naturally as possible for a posture assessment. For the walking task we will need to place 6 sensors on your back and arms and secure them with tape. These sensors are non-invasive and should not cause any discomfort or pain. In order to do this we will ask you to wear a shirt that we will provide you with that has a slit in the back. This is so we can see your spine and feel where the sensors are being placed. You will also be asked to take part in some physical tasks and

answer questions, which will be familiar to you from your visits to your consultant neurologist.

Your participation in the research is warmly welcomed, but if you feel you'd rather not take part in something, even if you said yes at the beginning, you do not have to. You may withdraw at any time. If you don't take part in the research, you may still take part in the dance class.

For any participants who have a pacemaker, deep brain stimulation implant, or any other electronic implant:

To the best of our knowledge and according to the information provided by the manufacturer, the electromagnetic tracking device that will be used to measure rigidity and posture should not have any adverse effects on any cardiovascular implant. Please ask the investigators if you have any questions and you should be aware of any potential risk, no matter how negligible it is. Regarding deep brain stimulators, it is strongly advised that you discuss this study with your doctor before consenting to take part in the physical measurements.

The research from the research conducted will be published and you have the right to remain anonymous within those publications, unless you would like to be credited. Your results from the physical measurements and questionnaires will remain anonymous.

Principal Investigator Contact Details:

Dr. Sara Houston
Department of Dance
Froebel College
University of Roehampton
Roehampton Lane
London
SW15 5PJ

Email: sara.houston@roehampton.ac.uk
Telephone: 020 8392 3243

Please tick where appropriate:

I confirm that I meet all of the eligibility criteria listed in the briefing paper

☐

I am content with being filmed as part of the research. I understand the footage will only be used for research and educational purposes.

☐

I would like to take part in the posture and gait measurements.
I am aware of the steps I need to take and the risks that are involved, however small they may be, if I am to carry out these measurements with a cardiovascular or deep brain stimulation implant.

☐

- I am content with having my height and weight measurements taken for the purposes of accurate data analysis ☐
- I would like to complete the Mini Mental State Exam ☐
- I would like to complete the Unified Parkinson's Disease Rating Scale ☐
- I would like to take part in the interviews ☐
- I would like to keep a diary ☐
- I would like to complete the balance confidence questionnaire ☐
- I would like to complete the McRae dance for Parkinson's questionnaire ☐

Consent Statement:

I agree to take part in this research, and am aware that I am free to withdraw at any point. I understand that the information I provide will be treated in confidence by the investigator and that my identity will be protected in the publication of any findings, unless I would like my name to be credited.

Name

Signature

Date

Please only sign below if, in addition, you would like to be known by either your first name or full name in any published research, rather than being anonymous (please note that your results from any physical measurements or questionnaires will remain anonymous):

Name you would like to be known by.....

Signature.....

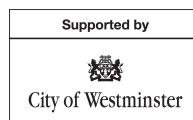
Date.....

Please note: if you have a concern about any aspect of your participation or any other queries please raise this with the investigator. However if you would like to contact an independent party please contact the Head of Department.

Head of Department Contact Details:

*Mr. Toby Bennett
Head of Department
Department of Dance
Froebel College
University of Roehampton
Roehampton Lane
London
SW15 5PJ
Email: t.bennett@roehampton.ac.uk
Telephone: 020 8392 3671*

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Appendix 6: Research Briefing Paper for Control Participants



Title of Research Project:

English National Ballet *Dance for Parkinson's*: An Investigative Study Part 2

Brief Description of Research Project for Non-Dancing Group:

English National Ballet has asked Dr. Sara Houston and Ashley McGill from Department of Dance, University of Roehampton to conduct research on the impact of dancing for people with Parkinson's. In order to conduct reliable and valid research that can say something significant about dance for people with Parkinson's, it is necessary to carry out our research methods with other people who are not taking part in the dance sessions. From this the researchers will be able to say more about whether any changes seen in the dancing group are due to the dancing or due to chance.

Ashley McGill, in collaboration with Professor Raymond Lee, Department of Life Sciences, University of Roehampton, would like to carry out some physical measurements with you focusing on stability, rigidity, posture and general health and well-being. A single testing session should take no longer than 1.5 hours and the aim is to do approximately 3 testing sessions per year. The venue is yet to be confirmed but we will try our best to accommodate you and carry out any testing sessions in your area when possible. Travel costs to and from the testing sessions will be covered or reimbursed and there are no other further costs to take part in this study.

In order to take part in the research you should:

- **not be taking part in any dance sessions on a regular basis for the duration of the project**
- be diagnosed with Parkinson's
- not have any current injury to the back, or have had recent surgery that would affect the movement of the back.
- be able to walk, or attempt to walk, without an aid, or feel reasonably confident that you can attempt the following measurements with support from other helpers if necessary.
- be aged 55 or over
- be able to communicate effectively, with no signs of dementia
- be aware that the postural and rigidity measurements involve an electromagnetic tracking device. This note is important to anybody who has an electronic implant (e.g. pacemaker or deep brain stimulator). To the best of our knowledge and according to the information provided by the manufacturer, the electromagnetic tracking device that will be used to measure rigidity and posture should not have any adverse effects on any cardiovascular implant (e.g. pacemaker). Please ask the investigators if you have any questions and you should be aware of any

potential risk, no matter how matter how negligible it is. Regarding deep brain stimulators, it is strongly advised that you discuss this study with your doctor before consenting to take part in the physical measurements.

- tell us if you are allergic to sticking plaster.

Your participation in the research is warmly welcomed, but if you feel you'd rather not take part in something, even if you said yes at the beginning, you do not have to. You may withdraw at any time. The researchers will disseminate the findings through various publications, reports, and presentations at the end of the project so that participants and the public can benefit from the work.

Below is a list of the measurements that Ashley will be doing and what would be required from you as a participant:

3) Posture

For this measurement I will ask you to wear a shirt that I will provide you with that has a slit in the back so that I can look at your spine. I will need you to stand as naturally as possible as I trace a small sensor up and down your spine. In order to do this accurately I will need to feel your back and sense where certain parts of the spine are before I place the sensors on you. A physiotherapist will help me to identify specific points along your spine and we will place small stickers on these points for accurate measurement.

I will also need to take a quick picture of you standing from the front view and from the side view.

4) Gait and Stability

For this measurement I will ask you to walk for approximately 10-15 steps and then turn around and go back the other way. This will need to be done about 3 times over. Before this walk I will need to attach 6 sensors to you (2 on the back, 2 on the left arm, and 2 on the right arm). All sensors are non-invasive and should cause no pain or discomfort. They will be attached with the use of double-sided tape and it is essential that you make the researchers aware of any allergic reactions to tape that you may have suffered previously. In order to do this I will ask you to wear a shirt that I will provide you with that has a slit in the back. This is so I can see your spine and feel where I am placing the sensors.

Please come wearing a top and trousers/skirt and, if possible, please wear trousers or a skirt with an elasticated waist band, which is easy to move slightly to accommodate the sensor. I will need to be in contact with this part of your back in order to secure the sensor. If you realize you don't feel comfortable with this, please feel free to talk with Sara or myself about ways that will help you feel more comfortable. In order to carry out the necessary calculations during data analysis, researcher (Ashley) will need to take a basic height and weight measurement before placing the sensors on your back and arms. If you do not feel comfortable with the weight and height measurements and do

not want to have these taken, you can still take part in all other aspects of the research

Additional Measurements

1) Unified Parkinson's Disease Rating Scale (UPDRS)

I would also like to look at the UPDRS. This scale is used by physicians to assess your Hoehn and Yahr score and looks at a variety of things including mental and physical health, ease of carrying out everyday activities, and further questions looking at stiffness, posture, and coordination. Some parts of the scale are looked at through a questionnaire and for other components you will be asked to try out a few small motor tasks.

2) Mini-Mental State Exam

This short test (approximately 5 minutes in length) has been used in previous research to assess cognitive and mental functioning.

You will be asked some questions by a physiotherapist. Questions will focus on things like naming objects in the room and spelling a common word backwards.

3) Balance confidence

Balance confidence plays a huge role in how stable we feel on any given day. I would like to look at this using the Activities-specific balance confidence scale. This scale has 16 items in a questionnaire format that ask you to answer how confident you feel about your stability in various different situations (i.e. Walking up/down stairs or picking up something off of the floor).

4) Interviews

I would like to conduct some interviews with you. These semi-structured interviews will focus on discussing how you feel in relation to the physical and mental components that I am looking at in the above measurements. I would also like to talk about any physical activities that you have been taking part in or have taken part in recently and if you found they helped you to cope with the symptoms of Parkinson's.

If you have any further questions about these measurements or you would like to sign up to be a part of the project, please contact me via email at Ashley.McGill@roehampton.ac.uk or call me at 077 6525 6213.

Principal Investigator Contact Details:

Dr. Sara Houston
Department of Dance

Email: sara.houston@roehampton.ac.uk
Telephone: 020 8392 3243

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Appendix 7: Research Consent Form for Control Participants



ETHICS COMMITTEE

PARTICIPANT CONSENT FORM (Control group)

Title of Research Project:

English National Ballet *Dance for Parkinson's*: An Investigative Study Part 2

Brief Description of Research Project:

English National Ballet has asked Dr. Sara Houston and Ashley McGill from Department of Dance, University of Roehampton to conduct research on the impact of dancing for people with Parkinson's. In order to conduct reliable and valid research that can say something significant about dance for people with Parkinson's, it is necessary to carry out our research methods with other people who are not taking part in the dance sessions. From this the researchers will be able to say more about whether any changes seen in the dancing group are due to the dancing or due to chance. The research will be carried out in collaboration with Professor Raymond Lee, Department of Life Sciences, University of Roehampton.

The physical measurements, questionnaires and interview will be carried out at a venue near to where you live.

For the physical measurements you will be asked to carry out a simple walking task and stand as naturally as possible for a posture assessment. For the walking task we will need to place 6 sensors on your back and arms and secure them with tape. These sensors are non-invasive and should not cause any discomfort or pain. In order to do this we will ask you to wear a shirt that we will provide you with that has a slit in the back. This is so we can see your spine and feel where the sensors are being placed. You will also be asked to take part in some physical tasks and answer questions, which will be familiar to you from your visits to your consultant neurologist.

Your participation in the research is warmly welcomed, but if you feel you'd rather not take part in something, even if you said yes at the beginning, you do not have to. You may withdraw at any time.

For any participants who have a pacemaker, deep brain stimulation implant, or any other electronic implant:

To the best of our knowledge and according to the information provided by the manufacturer, the electromagnetic tracking device that will be used to measure rigidity and posture should not have any adverse effects on any cardiovascular implant. Please ask the investigators if you have any questions and you should be aware of any potential risk, no matter how matter how negligible it is. Regarding deep brain stimulators, it is strongly advised that you discuss this study with your doctor before consenting to take part in the physical measurements.

The results from the research conducted will be published and you have the right to remain anonymous within those publications, unless you would like to be credited. Your results from the physical measurements and questionnaires will remain anonymous.

Principal Investigator Contact Details:

Dr. Sara Houston
Department of Dance
Froebel College
University of Roehampton
Roehampton Lane
London
SW15 5PJ

Email: sara.houston@roehampton.ac.uk
Telephone: 020 8392 3243

Please tick where appropriate:

I confirm that I meet all of the eligibility criteria listed in the briefing paper

☐

I would like to take part in the posture and gait measurements.
I am aware of the steps I need to take and the risks that are involved, however small they may be, if I am to carry out these measurements with a cardiovascular or deep brain stimulation implant.

☐

I am content with having my height and weight measurements
taken for the purposes of accurate data analysis

☐

I would like to complete the Mini Mental State Exam

☐

I would like to take part in the interview

☐

I would like to complete the Unified Parkinson's Disease Rating Scale

☐

I would like to complete the Balance Confidence Questionnaire
I agree to take part in this research, and am aware that I am free to
withdraw at any point. I understand that the information I provide will be
treated in confidence by the investigator and that my identity will be
protected in the publication of any findings.

☐

Signature: _____

Date: _____

Name printed: _____

Please note: if you have a concern about any aspect of your participation or any other queries please raise this with the investigator. However if you would like to contact an independent party please contact the Head of Department.

Head of Department Contact Details:

*Mr. Toby Bennett
Head of Department
Department of Dance
Froebel College
University of Roehampton
Roehampton Lane
London
SW15 5PJ
Email: t.bennett@roehampton.ac.uk
Telephone: 020 8392 3671*

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Appendix 8: Participant Health and Information Sheet



Number:

PARTICIPANT INFORMATION FORM (to be handed back to the researchers)

English National Ballet *Dance for Parkinson's*: An Investigative Study Part 2

Name: _____

Age: _____

Gender: Male Female

Please circle

Years since being diagnosed with Parkinson's: _____

Stage of Parkinson's (if known): _____

Any other medical conditions: Yes No

Please circle

If yes, please specify the condition)

**Fractures dislocation or injuries of the trunk in the last 12 months
requiring medical or surgical treatment:**

Other neurological conditions:

**Vestibular disorders (problems or infections in the inner ear affecting
balance ability):**

Other medical conditions:

Do you have a skin allergy to adhesive tape? Yes No

Please circle

Physical activities:

Over the past 7 days, how often did you take a walk outside your home or yard for any reason? For example, for fun or exercise, walking to work, walking the dog, etc?

Please circle

- 0. Never
- 1. Seldom (1-2 days)
- 2. Sometimes (3-4 days)
- 3. Often (5-7 days)

If you have answered 1, 2 or 3:

On average, how many hours per day did you spend walking?

Please circle

- Less than 1 hour
- 1 but less than 2 hours
- 2-4 hours
- More than 4 hours

Number of falls in the last 12 months: _____

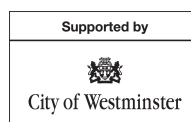
(A fall is considered to have happened if you have inadvertently or unintentionally come to rest on the ground or another lower level such as a chair, toilet, or bed.)

Current Medications (including number of daily doses):

Note: In accordance with the project consent form approved by Roehampton University Ethics this information will be treated in confidence by the investigator and your identity will be protected in the publication of any findings.

If you have any further questions about these measurements please do not hesitate to contact Sara or Ashley or talk to us in class. Our email addresses are: sara.houston@roehampton.ac.uk and Ashley.McGill@roehampton.ac.uk

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Appendix 9: Activity Levels, Attendance, and Fall Rates

Table 7.1 Index of Activity

Participant Number	Sep-12	Dec-12	Apr-13	Jul-13	Dec-13	Apr-14	Jul-14
Dancing Participants							
101	6	3	4	2	X	2	X
102	6	4	3	X	X	6	6
103	4	4	X	6	X	4	3
104	3	3	X	3	3	3	X
105	8	2	1	X	X	X	2
106	X	8	1	0	X	X	X
107	6	4	6	3	X	X	X
108	X	X	3	6	3	3	3
109	6	X	X	6	4	4	1
110	X	9	6	9	6	6	X
111	2	1	2	1	1	1	4
112	6	9	9	9	9	9	9
113	X	X	2	2	X	3	1
114	6	6	6	6	6	6	6
115	6	4	3	2	3	4	4
116	6	6	6	3	X	X	6
117	X	X	6	9	7.5	X	X
118	6	X	6	3	2	6	0
119	3	3	1	3	1	2	3
120	3	3	3	6	6	X	3
121	3	3	6	3	3	3	3
122	X	1	3	4	9	3	6
123	X	3	3	2	6	6	3
124	1	2	3	2	X	X	1
125	X	X	X	6	12	6	2
Control Participants							
201	X	X	4	3	6	9	6
202	X	X	1	2	1	1	0
203	X	9	4	2	3	2	2
204	2	2	2	1	2	X	X
205	3	3	3	X	3	3	3
206	2	1	1	X	4	X	2
207	9	X	X	6	X	6	9
208	3	3	3	3	3	3	2
209	X	0	1	1	X	0	1
210	X	12	9	6	9	6	6
211	X	X	4	1	2	X	0
212	6	3	6	6	6	3	3
213	6	9	8	4	12	6	4
214	4	4	4	2	X	0	0
215	X	X	X	X	6	6	9

* The numbers in the above chart represent an index of activity that has been calculated by multiplying the participants' physical activity rating and hours of activity per day as seen on the Health and Information sheet (Appendix 7)

* An "X" denotes that we do not have this information for the participant at that particular testing point

Table 7.2 Number of Falls Experienced Across Study

Partiipant Number	Sep-12	Dec-12	Apr-13	Jul-13	Dec-13	Apr-14	Jul-14
Dancing Participants							
101	8	5	5	4	X	10	X
102	4	0	2	X	X	3	0
103	0	0	X	4	X	1	0
104	0	0	X	0	0	0	X
105	15	10	2	X	X	X	
106	X	0	0	0	X	X	1
107	0	2	0	3	X	X	X
108	-----	-----	0	1	1	0	1
109	0	X	X	0	10	2	12
110	X	2	0	0	1	0	X
111	2 per week	X	60	4 per day	250	2 per day	25
112	0	0	0	0	0	0	0
113	-----	-----	6	7	X	7	X
114	1	5	7	2	1	2	2
115	1	0	0	1	2	2	1
116	1	0	0	0	X	X	1
117	-----	-----	0	0	0	X	X
118	2	X	1	1	0	1	
119	0	0	0	0	0	0	0
120	1 per day	1 per day	1 per day	1 per day	1 per day	X	1 per day
121	0	0	0	0	0	0	0
122	-----	4	12	2	3	2	3
123	-----	0	0	1	0	0	0
124	0	0	0	0	X	X	1
125	-----	-----	-----	0	0	0	0
Control Participants							
201	-----	-----	0	0	0	0	0
202	-----	-----	1	2	3	3	4
203	-----	3	0	1	0	1	1
204	7	3	3	5	5	X	X
205	1	1	0	X	1	2	0
206	0	0	0	X	4	X	0
207	0			1	X	0	1
208	0	0	1	4	1	0	0
209	2	4	5	0	X	0	1
210	-----	0	0	0	0	0	0
211	-----	-----	1	5	0	X	
212	0	0	0	0	0	0	0
213	5	0	1	1	1	0	0
214	X	X	3	30 per week	X	20	20
215	-----	-----	-----	-----	2	0	0

* Please note: the dashed lines represent when a participant had not yet started the project. An “X” denotes that we do not have this information for the participant at that particular testing point.

This is particularly important as the first time a participant was tested they were asked how many falls they had suffered across the previous 12 months. However, after that subsequent health and information sheets asked participants about the number of falls experienced since the last testing point which ranged from 3-5 months. As such, the numbers in the chart represent falls across different time periods.

* It is clear that some participants had difficulty interpreting what was meant by a “fall” for this particular question.

Table 7.3 Percentage of Ballet Classes Attended for Dancing Participants

Participant Number	Autumn 2012	Spring 2013	Summer 2013	Autumn 2013	Spring 2014	Summer 2014
101	85.71	75.00	60.00	36.36	0.00	63.64
102	57.14	62.50	40.00	9.09	54.55	81.82
103	64.29	37.50	80.00	54.55	100.00	63.64
104	100.00	100.00	80.00	90.91	100.00	90.91
105	85.71	87.50	80.00	81.82	81.82	45.45
106	71.43	87.50	60.00	18.18	36.36	0.00
107	85.71	100.00	40.00	0.00	0.00	0.00
108	85.71	75.00	70.00	81.82	81.82	54.55
109	71.43	75.00	90.00	81.82	100.00	63.64
110	50.00	75.00	60.00	81.82	63.64	36.36
111	92.86	87.50	90.00	100.00	81.82	90.91
112	78.57	87.50	70.00	54.55	90.91	81.82
113	21.43	75.00	60.00	54.55	72.73	45.45
114	78.57	87.50	90.00	90.91	81.82	54.55
115	92.86	100.00	100.00	90.91	100.00	100.00
116	92.86	100.00	90.00	63.64	0.00	90.91
117	57.14	25.00	50.00	36.36	54.55	0.00
118	64.29	100.00	60.00	72.73	81.82	81.82
119	71.43	12.50	90.00	63.64	18.18	54.55
120	71.43	75.00	50.00	63.64	27.27	36.36
121	85.71	100.00	100.00	90.91	81.82	100.00
122	92.86	87.50	70.00	45.45	81.82	90.91
123	64.29	75.00	60.00	72.73	100.00	63.64
124	57.14	62.50	70.00	36.36	0.00	36.36
125	0.00	0.00	60.00	90.91	100.00	90.91

Appendix 10: Volunteer Briefing Paper



Volunteer Briefing Paper

Title of Research Project:

English National Ballet *Dance for Parkinson's*: An Investigative Study Part 2

Thank you for volunteering to help with the testing sessions for the Dance for Parkinson's Project. Below are a few points that we would like to bring to your attention prior to your volunteer day(s).

What is Parkinson's?

Parkinson's is a neurodegenerative disease resulting from the depletion of the chemical dopamine in the basal ganglia of the brain. The lack of dopamine interferes with the ability to initiate movement, to keep movement going, or, contrariwise, to stop moving voluntarily. Parkinson's, therefore, can curtail the implementation of everyday tasks and actions.

Symptoms can vary greatly from one person to another. Some of the more common symptoms include:

- Tremor
- Rigidity or stiffness in muscles
- Slowness of movement (bradykinesia)
- A hurried, shuffling walk (festination)
- Lack of co-ordination, where an arm or arms stop swinging whilst walking
- 'Freezing', where people suddenly cannot move despite wanting to
- Change in posture from a more upright, vertical stance to a more stooped and curved line in the thoracic spine.
- The voice may become quieter
- Facial expression may lessen
- Depression is common
- Difficulty with everyday actions such as writing and dressing

Many people with Parkinson's lose balance easily and are at risk of falling regularly. Multi-tasking is often difficult. Neuromuscular tension and pain is common. There are a range of medicines prescribed to ease symptoms or to help other drugs metabolise. Many of these usually need to be taken several times a day and with continued use can become unreliable; many people also experience uncontrollable movement (dyskinesia).

Parkinson's is a progressive, degenerative condition for which there is no cure. The disease does not progress in a linear fashion. Some people may

experience periods where they feel more affected by Parkinson's than at other times. Even in a single day people may have 'off' and 'on' periods; 'off' periods being moments where symptoms are much worse than 'on' periods.

Houston & McGill (2010). English National Ballet Dance for Parkinson's: An investigative study (report)

Things to keep in mind:

- Although these individuals have Parkinson's, there are still things that they can do on their own and it is important to respect this fact. Please ask if they need help with something rather than assuming you need to do everything for them. Some individuals may also bring a friend, family member, or carer with them.
- Please be aware of any participants who look unstable on the day and may need someone to stand by their side for safety. It is always good to have a chair by the side as well in case they want to sit for a moment.
- If someone does happen to fall, please ask them if they would like help first and wait for them to instruct rather than trying to pull them up on your own.
- Although some do not mind talking about their Parkinson's, it is always best to try and start conversations with topics such as how they are enjoying the dance sessions (if they are dancing participants) or if they are doing anything exciting throughout the week or on the weekend. If they wish to talk about their symptoms or medications please wait for them to initiate the conversation.
- Due to instability it is always best to avoid walking backwards so when needing to turn and walk the other way (as is needed in one of the physical measurements) please help them turn slowly and safely so that they do not stumble backwards.

For those volunteers helping the physiotherapist with her measurements:

At this station Katherine Watkins will be carrying out the following measurements:

- 1) The Unified Parkinson's Disease Rating Scale (looking at non-motor and motor symptoms of Parkinson's and rating the severity of these symptoms)
- 2) The Mini-mental state exam

At this station Katherine may need help with the following:

- 1) Providing support for participants during the motor examination of the Unified Parkinson's Disease rating scale. Some tasks may require participants to be in an unstable position and she will need help to make sure they are supported and safe.
- 2) Video-taping the motor examination portion of the UPDRS scale.

For those volunteers helping with the physical measurements:

At this station we will be doing the following:

- 1) Posture assessment

- 2) Walking (Gait) analysis that requires sensors to be placed on the participant
- 3) Administering a balance confidence scale

At this station Ashley will need help with the following:

- 1) Getting tape ready for the sensors that will be placed on the participant
- 2) Helping with the posture assessment by pressing the record/stop buttons on the computer when asked (I will save the data each time).
- 3) Helping with the walking (gait) test by pressing the record and stop buttons on the computer (I will save the data each time) and providing support for the participant as he or she walks.

For those volunteers who are runners for all stations:

Please be available for people who are arriving at ENB and direct them to the waiting room. Here you can offer tea/coffee if they are early for their measurements and have a chat with them. Participants will also be offered tea/coffee at the end of their testing session so it would be lovely if you could help with this.

It is possible that someone may need help with changing into the t-shirt that we will be providing on the day. At this time it does not seem that any participants will be needing this help but if this is the case please be mindful of their stability and gentle when helping. If any participants need to leave the room to use the restroom please help direct them to the appropriate place.

As the day progresses there will likely be things that come up that I may need help with.

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Appendix 11: Interview Transcriptions

Participant 121 (Case Study One)

A – Do you want anything M? Water...coffee?

121 – No, I've got some water in my bag.

A – Ok, good stuff. So for the interviews I have been doing so far I've had kind of two sections that I have focused on. The first is...one of the main questions that I have been getting in the research so far is, what is it about dance that makes this so important, in comparison to other physical activities? And I can get what people are saying. So a lot of people are saying well of course physical activity would help a group of people with Parkinson's because any physical activity would help to a certain extent you would think. It's better than doing nothing, right? (or so the perception is this!)

121 – Yup!

A- So they are saying what is it about dance that you would encourage that over possibly other forms of activity like Pilates, like Tai Chi, these kind of things. And they by no means are saying that, you know, you should say one is better than the other. They're just saying, you know, in order to actually have a whole project about dance for Parkinson's, how can you say that this is something that is equally as good or possibly, you can get additional benefits from doing something like dance as opposed to other exercise forms? So it's kind of been... it's something that I really feel like I need to address in the project and in the research to say, ok yes it is a physical activity and yes it may help with things like balance and strength, you know, loosening up a certain flexibility in the spine perhaps. And these are the things we are looking at in your physical measurements. But then there is this questions of... can these things be addressed in other physical activities, possibly, and what is it about dance that kind of is a little bit...that has an additional benefit? Is there anything else that dance is providing that these other activities wouldn't? So it's an interesting thought. So that's kind of the first section that I wanted to touch on and I guess the first place to start is do you feel that the dancing is helping you with anything so far physically and or mentally? And what are those things if you could verbalize them. Umm, do you think it is giving you anything in terms of benefits really?

121 – Well the bit that I am always most impressed with is when they get people walking across the room.

A – I know, it's incredible!

121 – And then you compare the way they walk when they have the music playing and their asked to stride out across the room.

A – Yup, Yup

121 – And you can see that if the music wasn't there, they would be walking completely differently.

A – It is so true, yup!

121- And another thing is that with Parkinson's, people seem to lack coordination to remember that it is the left hand that goes forward when the right foot goes forward. And if you don't give them the music, and you ask them to walk, then they're much more likely to be uncoordinated.

A- Uncoordinated but with the music, music kind of

121 – So the music gives them better rhythm, better coordination, better speed I think as well.

A – Absolutely, I think so. They're pace seems to be...you have to keep your pace if you want to keep in time with the music, right?

121 – Yes, you don't have to think 'am I in time with the music?' You just set out and it kind of happens!

A – Yup, it's really interesting.

121 – It always surprises me because when I first started doing it I was thinking that I got to keep in time with the music.

A – Yup!

121- And now I just came to realise you don't have to think about it.

A- No you really don't.

121- I'm no dancer but I do definitely find that I respond to the music

A – That is an excellent point. I like how you said you don't have to think about it. You don't have to think too much about it and sometimes I feel that that maybe, the thinking too much about it is the, is the part that everybody gets a little bit stuck on or frozen on. And if it's just don't think about it, just let it happen there's a little bit of freedom that allows this coordination to come out, that allows this freedom.

121 – Ya that's what I think!

A – Ya!

121- Because you can think too hard about something.

A – You can!

121 – And you can think so hard that you're standing there thinking right which bit of me should move.

A – Ya exactly, exactly, and it just happens. I agree!

121 – And if you don't have to think then, I wouldn't...I haven't suffered from freezing but I would think that the music would help. Like just watching Jane D'Angelo. Turns up in her chair and then turn on the music and she's up.

A- Boom, yup. It's interesting, the music has come up as a very common thread through all of the interviews so far. And it's one of the things that, I think...I would be...I'm almost like 100% sure that every single person has stated to me, it's the music! The music is what adds this additional thing. It's an amazing kind of magical thing that happens when you're asked to move to music and a lot of people have said you know generally Parkinson's physicians, GP's, whoever you're dealing with would try to encourage things like counting to get the walking better or saying right, left, right, left, or that kind of thing.

121 – Ya, but again, that can confuse people!

A – Exactly it can confuse people and...

121 – And the music does it without people needing to think.

A – Exactly, you don't need to think about the, the counting, you don't need to think about the numbers, or about the right left right left, you just let it happen.

121 – Just go with it, go with the flow. The other exercises are good because, umm, some of the ones we were doing last term where you practiced walking backwards.

A – Ya I know!

121 – With the security of holding on to someone. And there are a lot of people who seemed really scared of walking backwards.

A – Absolutely, it's a scary thing!

121 – But when you've got the music playing and being in contact with another person then people can manage to do that and I'm sure if there were no music, that would be more difficult as well.

A – I know what you mean. Yes absolutely. I think the music, and you said touch as well, so the music and support of somebody else.

121 – The other person...when you're holding on to the arms of somebody, if they were to want to fall over, you probably couldn't hold them. But, just the fact that they're in contact gives people the impression that they're safe.

A – That's a good point actually. Because they're... I mean there is a certain amount of trust that you're putting there and you know that the other person may not be able to take on your full weight if you were to happen to stumble but just the fact that that touch is there, makes people more confident that they can.

121- I think so, ya!

A – Ya (moment to write....). It's an interesting point. It's something that in the report we talked about that you know we felt that in the short period of time that the pilot project happened, the very first project that we did, where we used the Fullerton Advanced Balance Scale and did all of those different tasks. And we saw a good improvement there with the people that we were looking at specifically and it was a significant improvement. And so that was great and at the end of it all you could kind of suggest that it seems balance has improved across this time. Which may be the case but sometimes...and both Sara and I felt that with the fact that we were doing one class a week, and we had a large break in between as well, it was basically 6 weeks and then another 6 weeks that we were doing our work, we weren't quite sure if it was the mechanisms that controlled balance that were affected or benefited or if it was the confidence of individuals in the group. That perhaps they felt more confident to attempt things? Ummm, and that they felt that they had found a way that "oh I could do this!" And maybe they were able to do it initially anyways but the confidence wasn't there. Do you feel like that is something that maybe has happened or do you feel like generally it is the physical, there's maybe a physical change that is happening?

121 – No I think confidence plays a big part because we've seen people like M. They seem to have trouble walking towards the bus stop but you put her down in one corner and someone holding on, sometimes she holds on to somebody, sometimes she doesn't, but she gets the confidence from just being...

A – just being in the room with people there (writing...). Absolutely, and do you feel there is anything else? Just with the sessions that you have been doing so far that anything else other than...so what do we have so far, umm the music is providing something that is really kind of important for what we are doing, so walking, coordination, rhythm, pace in gait. Walking backwards and having confidence with somebody there supporting is useful, and these things as I say may not be present in other exercise forms, so these are some things that are quite specific to dance which is exactly what I want to get at. Do you feel that there is anything else that's happening for you specifically?

121 – Well I find that I am getting better on following the instructions.

A – Great, great, yup!

121 – So I think this is something most people discovered and that is that the more you do, that you learn your little routine, the more easy it becomes to learn a routine. So ballet dancers are streets ahead of us. That's because they do a lot of practice.

A – It's true, there's a certain mental capacity there that, and I know this as well, you know it's this memorizing ability, after awhile, ummm, picking up speed, so the speed it takes to pick up something and follow instructions, and also memory recall. So sometimes I find that in terms of learning a long sequence sometimes it is difficult initially but the more you practice at doing routines, the easier it is to actually do a whole sequence of movements and not forget things.

121 – Like when we went to the 'Tate' (museum) to do our gig, everybody remembered, everybody worked in time music. And that was amazing!

A – It was amazing, it was an amazing experience I think for everybody. I think everybody came out of that just feeling like "Oh my gosh! This is something that is quite powerful". Umm, so better on following instructions. (writing...)

121 – So the movements can get more complicated and everybody just seems to follow along.

A - So it's nice because I also feel like we are being challenged in the classes that we do have and that there is progression as well. And I'm sure it's like this with other dance classes, it's just that ENB is really the only class that I have stuck with for this period of time. Umm, so things like Musical Moving or the Wimbledon group and that kind of thing, I am sure they are progressing as well. Ummm, but I only know ENB and from what I have seen in the ENB classes, it seems that we really are progressing and getting more complex and more challenge with each term that we've had. So, it's really great!

121 - Yup. And the seated exercises are designed to increase the flexibility, which is a good thing because a lot of people don't do much rotation.

A - It's true, and do you feel that that's helping you at all, that little bit of rotation that you do?

121 - Yes, ya I do!

A- And is this something that you feel...I mean the after effects? I certainly feel it after class, I can feel a little bit looser, and just like I've worked that area of the body. Like I can feel in my back and my arms. But then for me it kind of dissipates throughout the week.

121 - Yup!

A- Do you feel that as well, that it doesn't stick?

121 - Yup but the other advantage of the turning is that it gives confidence with the balance because if you don't have confidence that you can turn around you might be more inclined to take little steps, whereas if you've got the flexibility you've got greater movement.

A - It's such an important part of it (writing). That's great, excellent. So umm, we can always come back to more of these. I'm sure you could go on for ages

with the things that are helping. Is there anything else that specifically kind of pops out now? In terms of benefits, either psychological benefits, or physical benefits? We've got ah, rotation, feeling more flexible in the back, this is helping balance of course during gait, umm movements are getting more complicated and you're able to keep up and keep going with it

121- Well there's also the emotional side of it! It is related to the fact that, well I don't know if other people are like me, but I find that if I have things planned ahead for me to go to this is a good thing. And particularly things that you enjoy doing! It's kind of nice to not have a week that has no appointments at all.

A – Yup, absolutely!

121 – So just to meet with the other people, to enjoy the class is good in itself.

A – That's great to hear. I think we can all agree that we enjoy it.

121 - And people always seem cheerful when they arrive.

A – They do and I love it! It is just a really great atmosphere when you get here and everyone is really glad to see each other so I love it.

121 – And that seems to me to be quite a big part of it, all that.

A – It's true. I think the atmosphere we have and what Danielle has kind of created for us in terms of the atmosphere that we're in, umm, it makes a huge difference, a huge difference. I think there is a certain magic! And I have said this quite a bit, I feel that there is a certain magic with this group. We know each other so well now that it's umm, it's like a little family. And because as I say I don't know the other groups as well it could be a very similar spark that's happening there as well, umm, but I do feel that that's the case in this one as well.

121 – And everybody seems to notice when someone is doing better than usual and they comment upon it.

A – Encourage and support each other!

121 – Ya so there is quite a lot of support here for people.

A – So true. That's wonderful. So in terms of the other, are you doing any other activities at the moment, other than the dancing, and by this I mean like a constant thing, like dancing is a constant?

121 – The musical movement has stopped for the summer. Sometimes I do Pilates in Kensington and Chelsea group. Not always. Umm, and I've got a local gym that I go to.

A – Oh great!

121- I usually go for about half an hour a day.

A – Oh wonderful. And what kind of things do you do there?

121- Ummm there is a kind of stationary bicycle that I use. I use the weights and you can do simple exercises.

A – That's wonderful. Is there anything else that you do throughout the week?

121- Well at this gym they've got mats and several charts indicating stretches that you can do.

A - So you do some of those as well?

121 - Yup, and then I went to the contact improvisation course last year that was done by Hartford.

A - Oh really, did you? How was it?

121 - Ya, we spent a lot of time rolling around and so I still do some of the rolling around exercises because we've got mats on the floor in the gym. So I find that's quite useful.

A – Good for you!

121 – That helps turning over in bed I think.

A – You think so, ok.

121 – But it looks a bit daft if you just lie down and roll one way and then you roll back the other way.

A – I know but if it help you do things, like turn over in bed, this is all very important.

121 – Ya, and another good thing is that it gives you practice getting up so if you do ever fall over, which I haven't for a bit now, it means that I am quite capable of getting up if I fall over.

A – That is wonderful to hear that! These are exactly where I was going with this part here so you have kind of already done it for me.... to put these things into context. To say, how are these things helping you? Umm and what are they helping you with really? And these are kind of perfect examples. That's great, rolling over, practice getting up, turning in bed. Umm, is there anything else that you feel those gym exercises are giving you, umm, and this could be specific things like you've said or just developing fitness components like strength and...

121 - Just trying to keep muscles from deteriorating. Because as you get older if you don't use you strength you just lose it.

A – It's kind of that saying...

121 - Use it or lose it!

A – That's exactly it! Famous saying! It's a really good point actually. I think actually a lot of people, from what I understand anyway, a lot of people are doing these additional things to kind of keep things going. And do you feel, umm, that any of these things...would you say I guess these kind of exercises you do at the gym, I mean certainly things like rolling exercises, and turning over in bed, I can imagine that you are getting that benefit of being able to turn over in bed easier due to the exercises you are doing there?

121 – Yup!

A – More so than the exercises that you do in the dance class or would you say they are pretty equal?

121 - Well, they are good for different things. There is nothing.... contact improvisation you do rolling, we don't do rolling here!

A – Yes, no exactly!

121 – That would be a bit difficult I would think.

A – I think so, it would be a bit difficult to get everyone on the floor rolling around but...

121 - But everyone really does need a mat, rolling around on the hard floor is not much fun.

A – No not fun, that's still great though!

121 – So basically the 'sitting down' exercises are just like stretches to music (in dance class).

A – Exactly, that's exactly it. I think you're right when you say that everything is for different things. I think that is really where I am going with this, is that, meaning with all of the interviews so far is that a lot of people do other things like the Pilates with the support groups and that kind of thing. And these things are all...I mean dance is giving certain things like we talked about coordination, and a better gait, a better dynamic balance during gait because that's what we are focusing on. And it's all dependent on what the focus is, right, and our rotation is really helping the flexibility in the back.

121 – And that helps the walking!

A – And that helps the walking, so it is all connected and...

121 – Because you see some people walking without any rotation at all and it looks unnatural.

A – Like it's unnatural and it's stiff and you can imagine the body needs to be quite responsive to, umm... if there was a stumble, if there was something that tripped one up, the stiffness would not be helpful in terms of trying to catch yourself. I think there is a certain amount of reaction time and a certain amount of flexibility that needs to be there in order to catch oneself but also just to, to walk in a coordinated fashion. Umm, and there is quite a bit of research on that and that's what we're actually, exactly what we are trying to look at with our sensors that I put on the backs of everybody. So to see how much rotation is happening in the upper back and the lower back as we walk.

121 – Yup!

A – And to see if there is this kind of, generally what we're supposed to do at a certain pace is actually switch from more of an in-phase to a more out of phase walk which makes sense because as one arm swings forward that leg comes forward so it seems the pelvis is actually twisting one way and the arms are doing something else the other way and you're kind of going (demonstrate...) like that you know but just a smaller context. Of course we don't all walk like this (exaggerated demonstration...). But you know what I mean, like it's that kind of thing.

121 - Yup but those twisting exercises, they definitely help!

A – That's wonderful, well I'm going to move on to the second part. This is really great information and I think we've got a good amount of, umm... a good outlook on what it's doing for you. And if you can think of anything else just let me know, but we'll move on to the second bit and we can always come back to this near the end. So the second bit of the interview that I have kind of been doing with people is to look at, ummm, participation in society. So this is...it was basically based on a questionnaire actually. I am trying to, in the research, look at three different levels. And in the questionnaire that you filled out there is going to be questions about the functioning of the body and the mind, right? So these are things like how are our organs working? How our mind is working. So we are looking at those things, we are also looking at everyday activities and the ease of doing everyday activities. So that's kind of the second level. So the first level being organs, mind, brain, kind of the basic general body and mind, the second level, how is the Parkinson's possibly affecting everyday activities? And then the 3rd level is looking at how its affecting participation in society, so just general activities. You know these could be things like housework, going to get the groceries or doing things and hobbies that you would like to do, that kind of thing. So that's really the question I guess, is that do you feel that the Parkinson's is actually helping, or well... not helping but do you feel that the Parkinson's is stopping you doing anything that you would like to do?

121 – Well I don't know if it's just me but I find that umm, I don't have much energy. And I realise as you get older you lose energy.

A - Yes this is exactly it!

121 – But I think that the Parkinson's has basically accelerated ageing, quite frankly.

A – Yup, ok (writing...). This, umm, makes sense. It's, ummm, it's difficult to distinguish between ageing symptoms and Parkinson's symptoms sometimes.

121- Yup, and other ailments because it's hard to find somebody who just has the one ailment.

A – Yup I agree. And this is a major thing that you feel might be hindering things that you would like to do.

121 – Yup, it means that you can't plan to do too much in one day because you just end up feeling very tired.

A – Yup, it makes sense, exactly!

121 – And you see some drop off, during class.

A – Yup!

121 - I'm not quite there yet but I think that I probably get more sleep now than I used to because I just get tired. And when you get tired you don't feel like going out and socialising.

A – Nope, exactly you feel like being in and resting because you're just that much more tired. Ya, it's a cycle that's for sure.

121 – So on the other hand you can have too little to do in a day, which is depressing, or you can have too much to do which is tiring.

A – It is true!

121 - And it's almost impossible to get just the right amount in a day.

A – It is, yes, it is difficult.

121 - So you're not too tired out, you're not too depressed at the end of the day. That's the...its tricky!

A – It's a tricky balance to try and figure out what is too much and what's not to keep you motivated. Because I think the motivation goes down as well. If you're, ya, if you're feeling like a little low the motivation is really what's kicked there. It's the motivation to not...the motivation is low to do anything really, umm, and it completely makes sense of course. If you're going to be too tired, motivation is also low because you don't want to be too tired and exhausted.

121 – Ya so if someone says 'come out to Manchester for the day,' my reaction is going to be no thanks! I'm not going up there.

A – I know exactly what you mean!

121 – We used to go to Manchester for lunch to be with my brother and his family but he just doesn't realise that if I do that, and have the lunch and come back...

A - I was going to say, that is just exhausting. And that's a long trip for you too right? That's a very long trip so...

121 - You're sitting on a train for about 5 or 6 hours and that is...so you get that the travelling is tiring as well which I never would have thought of when I was younger.

A – No, I mean it was fine in terms of trains and just sitting there, that kind of thing. But the whole, everything to do with transportation these days is a lot, it's a lot walking everywhere and needing to sit that long is hard.

121 – And the other thing I find is that the things I normally do, I am quite happy to do but if something is new and different then I am a little bit more inclined to think what if this happens or what if that happens? And it's just something out of the norm. So I try to do things that I don't always do just to prevent, try to prevent myself from getting into a rut.

A – Yup that makes sense and trying to keep to the norm I guess.

121 – It's trying to keep your horizons open. If you stop never doing anything new you're just going to get to the point where you just sit in and go to the shops because you need the food.

A – Need the food...and that's pretty much it! Well it makes sense.

121 – And you can see that some people have gotten to that point in their life and they're not always the Parkinson's sufferers. Little old ladies dressing up to go to the shops and then come back and watch the television. That's old age.

A – It's old age, and this is just it. It's a very hard part of our research is to...I mean a lot of the symptoms that you see, not tremor no, but other things like increased fall risk, increased instability, these kind of things are also an older age problem. They're an ageing problem as well as a Parkinson's problem. So to distinguish or try to distinguish between the two is nearly impossible, umm, if we are dealing with Parkinson's people who are also older. So it's a little difficult, ya, to kind of say well is it the ageing or is it the Parkinson's or do we really have to distinguish? Can we just say this is the case and is dancing making it better at all? Is dancing helping at all to cope with something that is not as easy?

So I think, umm, from what I understand, it does seem to be. But through many different pathways and that's how we discuss it in the research is that these things are helping in a variety of different pathways physically and mentally because mentally it's possibly giving confidence that will allow us to walk better

and not be as worried about the falls, which would help, but also physically giving us tools to help walk better.

121 – Yes, several people have said to me that their not inclined to go out on their own but if the carer can't come for some reason and the object of the exercise is to come here, then they'll do it!

A - Ya I know, then they'll do it!

121 – So that shows that it's incentive because people like it, they like to come.

A – They like to come, and I had a few people say, can't remember who it was, but someone said that another participant in the class had told them one time, "I would do whatever it takes to get here in on a Saturday!"

121 – Yes that's what other people have told me too!

A – And it's such a wonderful drive, there's such a wonderful commitment that people have to it and it's just wonderful to see. Wonderful! And a lot of people have worked hard to create that atmosphere of course and Danielle has done a wonderful job and everybody else.

121 – Yes!

A – And all of you guys have done a wonderful job so it's everyone working together for a common goal that makes it so good. But I am glad to hear this. And you mentioned doing things independently, or having assistance. Do you do most things independently? These are things like groceries and that kind of thing or would you have a carer or assistant to help you with those things most of the time or your husband?

121 - Well, my husband and I usually go shopping, big shopping once a week so we take our backpacks and off we go. It means that we don't have to go out every day to do the shopping, we just take the backpacks and fill them up for the week.

A – That's wonderful! And I think another kind of part of this...it was all to do with the questionnaire, this kind of section of the interview and I've kind of brought the questionnaire into interview questions because I felt it was better to talk about them rather than have you guys check it off! That, this idea of umm, housemaking and things maybe that you would normally do in the house, umm you know, if you liked gardening before, don't' know if you liked gardening but if you did, do you still do those things or, ummm the...

121 – I have never liked gardening so I live in a flat so I don't have a garden now. I used to like going out walking, but since I got the...well it's mainly the osteoporosis. That I am a bit more scared of falling because the osteoporosis people have told me that I can't cycle because if I fell off my bike again I'd break something. So the osteoporosis limits your horizons as well.

A – Exactly, that’s true. Ok.

121 – So the combination of the lack of energy and the not wanting to fall over means that I don’t do quite a few of the things that I used to do, bicycling and walking that sort of stuff. And holidays are a bit tricky because that’s like the unknown.

A – Yes and we talked about the unknown being a little bit...it’s hard. I mean holidays as well! Well, I’ve just done it and it’s just such an upheaval.

121 – That’s one of the advantages of mixing with Parkinson’s people is because a lot of them have always been somewhere interesting and they talk about their trips and you think well, sounds ok!

A - Ya it’s true, I mean there are lots of lovely places to go and I’m sure they can be very accommodating but it’s the whole going to the airport, and all of that.

121 - And it’s the packing up, what do we take? What if this happens? Where’s the insurance?

A – It’s preparing right, it’s the whole thing of preparing for these things, yup!

121 – But then you hear of people who have strokes abroad and you think well, it’s not that much different from having a stroke at home but...

A – You’re not home, and it’s ya...

121 – It’s such a fuss palava trying to get treatment at hospitals abroad so it discourages you from going.

A – Yup absolutely!

121 – So this is why people need, umm, confidence boosting because other people of my age seem to be so much more about their holidays.

A – Ya it’s, this is just it, there’s a lot to do with the confidence, and we keep coming back to that and ...

121 - It is important!

A – It is, it is hugely important to show people that they can do, and the tools. Some of the things I have heard people say in terms of this specific exercise is...something I would do at home to reach something up high, I would think about rising and holding my tummy muscles and that kind of thing. Or if I need to get something from the floor I would do a plie down and get it. And these kind of things, I am just like ‘wow’! Sometimes you really think it is not just Saturday fun together, it’s Saturday is a fun day we are all together but there’s things that have been taken out of context and put into daily activities as well. Not out of context, this is what we want to happen, but you know what I mean? It’s taking it out of the dance class and bringing it home. It’s the same thing with the music as

well and rhythms from class and trying to bring that back if there's a problem at home with anything like freezing or walking. Sometimes people say they will remember the 'Romeo and Juliet' rhythm that we had initially. So these kind of things can help build confidence to a certain extent and hopefully those things just kind of build on top of each other to really allow the growth of confidence to happen. Ummm, but I do agree with you, it is a huge part of all of this.

121 – And even some of the stretching exercises where you sort of lean down to one side. It's kind of useful if you want to pick something up off of the floor because you know you can do it and you're not worried about capsizing.

A – This is exactly it, you've done it in class and this is something that you know how to manage in your body now because you've done it so many times. That's really great! I am glad to hear you are on the same page as that and that there are some things that are helping your confidence as well. I mean the twisting, the rotation, having the flexibility. Umm, and do you feel there has been a growth in your confidence since having taken part in the dance classes here?

121 – Ya, just the...just getting here is part of it and then.

A – That's actually quite a lot!

121 – And also to be able to compare yourself to people, well, comparing me against people my age who don't have Parkinson's is a whole different ball game than comparing me with people that do. So although by brother seems to be, he was older than me, but I seem to be older than him now! Whereas with these people, we all seem to be progressing at..

A – The same?

121 – More like the same rate!

A – Yup, I do agree. A lot of people have mentioned that as well is that looking at other people and seeing (...that they are not dissimilar). This is something that people have said is an advantage and disadvantage to the group settings and working with people. It is such a great group that everybody has mentioned that the group itself is something that is helpful, the support, the people there. But then sometimes people have addressed the issue that sometimes you will see someone else who is not doing well and that sometimes worries them and I can understand that. I can certainly understand that and I guess it is an important thing to remember that not everyone has the same pathways as well and everybody experiences Parkinson's in a different way. So just because someone else is in a different place in their life doesn't mean that you'd ever get there, that kind of thing. So it's an interesting thing.

121 – Ya I don't find it difficult seeing people worse off than myself because I know there are so many different types of the disease that you don't know which people's route you're going to follow.

A – Exactly, this is so true, and a few people brought that up and that's just it. It is such an individual thing that it is just impossible, we were talking about comparing to other people your own age and other people with Parkinson's and this comparison thing has come up before and it is interesting because there is this comparison but then there's also this, but this person has this pathway in Parkinson's and I will have a completely different path. It's true and we all compare to each other and it is good to see that you feel it is helping you confidence as well and it's aiding that!

Participant 115 (Case Study Two)

A – So what I have been doing with everyone so far is kind of focusing on two different kinds of questions or areas. The first of which is looking at dance, any connections you feel between dance, and any other benefits physical or mental that you feel you're getting as a result of the classes. And then going on to say anything else that you are doing other than dance, like Pilates. Some people are doing Tai Chi I think, so any other activities that you're doing and any benefits that you are getting from those. So maybe let's just start with the dancing that we've been doing for the past year and kind of links that you feel there are between the class and any changes that you've seen in yourself. Are there any connections that you feel or any changes that you feel are probably directly because of the dance classes?

115 – You know that I do 2 dance classes?

A – Yes, yes I do. You get more than most people, which is nice!

115 – So it's hard to obviously separate any physical changes as to which class is which.

A – Yup that's fine!

115 – Especially as they are kind of similar.

A – Ya are there any differences really between...?

115 – Well they're getting more different. I mean the classes... well the obvious difference is that the ENB class is much bigger. It's been up to...I would think we have had weeks where we have had up to 50 people there. I mean there must be something like about 70 odd people have come at one time or another, but certainly I am sure we have been up to about 50. And I think an average is probably...I mean recently it's around about 30, whereas Kentish Town is on an up at the moment in terms of numbers and it's sort of 16 to 19.

A – That's pretty good still!

115 – Whereas this time last year we would be 8 to 10. Ya, so it's probably doubled and we've now got 5 men which is the most men we've ever had.

A – Great!

115 – We only had one man for a long time and he moaned about it, whereas ENB's always been pretty even I suppose.

A – Pretty even, I would think so. I have never really noticed much of an imbalance.

115 – There are a lot of men.

A – There are a lot of men. I haven't noticed any imbalance actually of there being any more men or more females than males so, that's good. And so with it being bigger, does that change the experience of it do you think?

115 – I don't think that it...well it's hard to say that because I was in the small one first and I belonged to this group, Kensington and Chelsea. And through those two I got to know people, so I knew people before we started ENB so...I mean it may be that it's harder for the people who come to ENB cold as it were. It maybe is harder for them but I don't know, it is a very friendly class.

A – Very friendly isn't it, that is what everyone has been saying so far.

115 – But so is Kentish Town. And Joanne and Anna [Kentish Town Dance for Parkinson's teachers], it's been funny because they've been obsessing about the size of the rooms for, oh, the last 2 years. I mean as the numbers have got bigger they keep going on about there not being enough room to do the walks and they have endless meetings and chats about what they're going to do about getting more space. And they talked at one time about splitting the class into two and we got really upset about that. They picked up that we didn't really want the class split because an important part is the feeling within the group that we were, you know like the tribe that we had in the Rite of Spring (ENB class), you know I think that's kind of what we feel.

A – Ya, as well you should because it is about the social inclusion and I am sure they understand that and it's...

115 – And they had these meetings with the administrators there about maybe moving somewhere else, and we were all sort of (worried face), and the really silly thing about it was that the reason they wanted to move was that there wasn't a lot of room to do the walking basically. But the classes are an hour and a half long, and the walking bit is like 10 minutes at the most!

A – I was going to say, you guys can do a lot of other things!

115 – So to spoil the community feel for that, but I think it's finally dawned on them because...well maybe two things have really dawned on them. First of all they have these other classes now, they've got one in Edgware, they've got one in Hame, they've got one in Wimbledon, and they're all in big rooms apparently and they keep saying that "we like Kentish Town because it's small and we get to know everybody." And I'm sort of laughing and she's saying "I know, I know" this was yesterday, Monday, Joanne said, "I've been going on about getting bigger premises but I think we've realised that..." So I said "you promise you're going to stop going on about moving" and she said, "yes I think so". But she's decided that's a good feature of Kentish Town!

A – There you go! Turning a negative into a positive!

(other discussions about Kentish Town and ENB administration not related to interview questions)

115 – So we've got the two classes and I don't think I can separate between them.

A – No, nor should you. I mean in a way both sessions are dancing. Both are going to be very similar in what they do because there is a common ground in the Dance for Parkinson's network about what teachers will teach.

115 – I mean the big difference obviously is the connection between ENB and the repertoire and that's so exciting. And this year particularly because we've had Rite of Spring and Firebird, whereas...I mean I'm not really a big fan of Nutcracker and I know Danielle did her best to sell it to us.

A – I know, ya, we're both obsessed with Christmas!

115 – Ya I'm not that obsessed with Christmas and I can live without it. I mean I don't find the music terribly interesting. But all the rep we've done...I mean 'Romeo and Juliet' and that has a great score.

A – Yes it was such a great way to start off. I think everyone knows the characters so well that it was really easy to pull on.

115 – Yes it was very lucky to have that as our first repertoire but I mean smart to pick it rather than Swan Lake.

A – Absolutely, I think Swan Lake would have been much more difficult. If you can say with truth, "ok (embody) the anger of Mercutio," and we all know because we've seen plays and movies, you know exactly what you're trying to portray. Whereas Swan Lake is a bit different, so it was good. And are you doing any other activities other than the dancing and the Pilates? I know you're doing Pilates as well. Are there any other physical activities?

115 – No.

A – Ok. Because that's one of the issues I'm trying to deal with in my investigation is trying to determine what it is about the dancing. I think a lot of people are very aware of the fact that dancing probably could or will be beneficial, especially for this group of people. It's a physical activity, which is always going to be better than doing nothing at all and so the question that I'm getting a lot is, "well why would you encourage dance as opposed to other exercise regimes?"

115 – Because people will do it because they enjoy it more! It's the music basically.

A – I love that. It's the music! It's true, moving to music is different than a lot of other things that you are doing.

115 – Absolutely, so it will persist. I mean you put the music on and you're dancing and you can't help it! It's undoubtedly the music. I mean for me it is, certainly.

A – Good, I’m glad. I had this conversation with someone else in a different Parkinson’s support group the other day when I was trying to recruit new participants for a control group and this lady said, “do you mind me asking, why...why do I want to dance all the time?” (laughing). And I said “what do you mean?” and she said “well when I listen to a piece of music, you know, if you get that right piece of music you’re body just wants to dance.” And it seems innate in everybody.

115 – Well perhaps not in everybody (laugh)!

A – Well that’s true, some people don’t really have the coordination but...you know what I mean.

115 – And that fascinates me is what happens to people who don’t move in time to the music, what’s going on in their brains? We’ve got this guy at Kentish Town who, when we start to do the plie section and we’re doing that moving from side to side, he always moves in the opposite direction from everybody else, or regularly does anyway. And it’s as if...he doesn’t seem to be aware that we’re all going one way and he’s going the other way. Or if he is he doesn’t seem to be aware that that’s not the purpose of the exercise (laugh). I don’t know whether he doesn’t hear the music, because he’s sometimes out of time with the music as well.

A – Which could be the situation there.

115 – It could be, or whether it’s something to do with the Parkinson’s, that he can hear it in his head but he can’t make his body do it. But I mean he doesn’t seem to stop and try to right himself, which most people would do.

A – Most people would and I think people are often aware of what’s going on around them.

115 – And it’s almost every week that Joanne has to come running around and grab him by both hands to kind of steer him to the right sort of direction.

(More discussion hear about what is happening when this particular individual is not moving in time to the music and why that is happening – discussion about particular kinds of music out of discussion with Tom Isaacs)

115 – When we’re walking at Kentish Town, I mean we’ll do maybe three different kinds of walks. She’s had this thing about polonaise recently. So we had a polonaise walk, we’ve had a sort of syncopated, jaunty kind of walk, and we’ve had a big striding out kind of walk. And so we started out with the sort of jaunty walk the other day and she keeps saying this is difficult. Now I don’t find the jaunty walk difficult at all, if it’s heavily syncopated then I find that dead easy. I know what I’m doing, you know, the polonaise walk it’s got a strong rhythm. I can get into that! But just this sort of like, a marching stride, maybe with the right music I could do that, but most of the music she puts on for it doesn’t seem to quite fit with a big striding march and that, I feel confused as to what I am supposed to do really. And yet she thinks the stride is the easy one!

A – Ya, as she would probably because the syncopated is something that...well it can be pretty tricky for other people who are just used to a steady rhythm. Whereas, I understand that! The other day when we were using this really kind of jazzy music and we were marching to it but I wanted to do some sort of (jazzy walk with snaps).

115 – Well exactly, yes doing a march to it I actually found quite difficult because you thought, well, where do I fit?

A – that in...

115 – Ya exactly (laugh). I find those marches really difficult. I mean if they had proper marching music, some sort of military type music (maybe). But I find that quite odd.

A – Yes I understand what you're saying.

115 – Well if you do then it has absolutely nothing to do with Parkinson's.

A - No, I do. The other day when we were doing that I thought, hmm I don't know.

115 – It's usually quite fast as well and I was thinking, I don't think my arms go that fast.

A – Ya I was thinking that I could force myself to move in the way that we are being asked to move but that doesn't feel natural. And what we're looking for is a natural feeling of coordinated work.

(More discussion about the walks against the music in relation discussion above – not relevant for interview purposes)

A – Anything else that you can think of that the dancing provides that maybe doing....we were talking about Zumba and Zumba is very interestingly Latin dance movements and it's kind of more fitness so it's like an aerobics class but you're doing it to Latin music. And it has a few little dance moves in there.

115 – Well that could be fun. How we would all cope with aerobics I don't know. I mean, I am very conscious of the fact that I don't really ever get to the point of serious exercise because it's just very difficult.

A – And your not wanting to overexert yourself is a smart thing probably at this point. I was talking to someone else this morning and they were saying with a few things you just want to be careful that you're not going to overdo it because that then just carries on to a variety of other problems, so that makes sense.

115 – It would be good for us if it could be done slowly, gradually and safely because...I mean, I'm very conscious of the fact that I don't do that sort of exercise. I never really get to the point of being out of breath because you just don't have the juice in your legs to walk fast, but on the other hand, having said

that, thinking back to Rite of Spring, there were minutes and minutes and minutes of stamping, clapping and stamps. So we can when we build up to it.

A – Exactly, the proper gradual progression.

115 - So maybe we could do it if it was part of our...because that one that we're doing now in Firebird when we're dancing in a ring, is just as ambitious as the one that we did in the Tate museum. I mean I was looking around on Saturday. I mean, I don't know how many people with Parkinson's really can do it (laughing) but...

A – They were trying. I was looking around as well and it can be frustrating.

115 – Because there are a lot of people there who are not compromised by Parkinson's.

A – Yes and also it is a long piece really.

115 – And there's a lot to remember as well.

A – That's exactly what I was going to say, it's memory. It's a complex dance, it's a whole dance really and so to go on for that long not only physically but just memory wise, you're thinking what comes next. It can be exhausting just on the mental side.

115 – This term there were a lot of things. I mean they did a lot of new routines and didn't do them all often whereas previously we would have done the same thing every week for 12 weeks or whatever it is, whereas this term we would do 3 or 4 weeks and then she would say "let's have a new port de bras". And I did find that some of the movements I struggled with, this is the first time really that I, I don't always do them well but I can do them. But I found that...I can't shimmy at all! It would be nice to have a shimmy class!

A – Yes learn about the isolation of the shoulders. It's difficult that bit!

(more discussion about a particular movement done by an artist)

115 – The other movements I found difficult, there were some backwards movements, making sort of wings with the arms. Danielle has arms that sort of turn the right way to make this shape, which I don't. That was true and in 'Rite of Spring', some movements I just don't get the angles. I mean I could see what it is supposed to look like and I could look in the mirror and see I haven't done it but I can't make my arms do it!

A – Yes you're very right. I think they're trying to, which is great for me frankly because what they're doing is actually really following on from some of the things that I want to look at in the research, which is great, in terms of rigidity and stiffness in the torso. And so all of these kind of things that require you to go back and twist which can be very difficult for a lot of people and even this whole

posture thing as well that I am looking at, being able to lift up but also take the arms all the way up.

115 - And that can only be good for people like me who have got posture problems.

A – It's great for this!

115 – I mean I can do this (pushing chest forward and arms back) providing I can do it in the way that I can do it. It's just doing it in a certain way might be really difficult but when sometimes she has her hands on the chair and leans forward, a bit like in 'Titanic' (movie). If I approach it in the right way, I can do that pushing the chest out.

A – Yes but it's just the way that they did it made it much more difficult.

115 – It's just much harder when you need to twist, my shoulders presumably don't have that...

A – Range of motion, ya. I mean everyone is going to be different as well.

115 – I think it's relatively common in Parkinson's, shoulder problems because there seems to be... I'm sure I read somewhere that frozen shoulders are often a precursor and I had 2 or 3 frozen shoulders prior to getting Parkinson's.

A – I think the general stiffness and rigidity is a main problem and these frozen shoulders and often the stooping, it's all connected to this stiffness and we're getting closer together and not looser. And that's why we think the dancing...we can see it in the videos that we watched last time. And we didn't measure it last time, that's why I am trying to look at it this time. But when we watched the videos back we could clearly see progression. It was noticeable...the looseness.

115 - I don't think the rotation I find so difficult.

(discussion about some other people in class....)

P – I think it's great that we are being challenged. And it is great to see how excited they get when we actually do it (laughs)!

A – I know it is great!

115 – It's like a surprise that they challenged us and we actually did it.

A – Well that's great...! That was kind of the first part of what I wanted to talk about was just the dance classes themselves, any other physical activities that you're doing. But it's clear that the dancing is the most that you're doing. So the second part that I wanted to talk about, it's quite quick so we won't be too much longer, is this idea of independence in society and how independent you feel you are. Obviously something we can see with a variety of people is that there is a lot of assistance and caretaking that happens and one of the parts that we wanted to

look at in the research is to say “is there any change in participation in society?” So this comes at 3 levels and the first level we are looking at here is basically activities and chores that take you outside of the house. So this could be things like picking up groceries, picking up a prescription, going to get a book from the library...all of these kind of everyday things that people would do. Do you feel that you can do those things independently with no help or do you feel you need an assistant to do these things?

115 – I’ve never had any assistance. The only thing I don’t do that I used to is that when we go to the supermarket, we go together because PE drives and I gave up driving. I used to do the supermarket shopping on my own. I don’t like it. He would do it on his own but I do most of the cooking because I like doing most of the cooking and if you do that you kind of want to go buy the stuff yourself. He would go himself and buy it but it would be more of an impulse buy, but he can’t really buy what I want to cook. You get inspiration about what you want to cook by doing the shopping and being there

A – Exactly!

(More personal discussion about this)

115 – apart from that I don’t think there is anything else that I need help with

A – Great, these are all kind of questions about how much assistance is needed but I realise that you are quite independent and can do things on your own and travel on your own, on the buses and that kind of stuff. So the other question was kind of active homemaking which cooking comes in to, so these are things like cooking, cleaning, any maintenance that needs to be done on the house, and this is a funny question because some people just don’t do it because the other person in the house has always done it. But the idea is to think about these things in relation to your Parkinson’s in saying that is the Parkinson’s stopping you from doing any kind of homemaking or do you feel that you could do everything quite well if you needed to?

115 – That’s a good question. Umm, our house is a tip (laughing)!

A – Uurs is at the moment right now too!

115 – Now on the other hand, I can’t pretend really that it would be pristine, tidy, and neat if I didn’t have Parkinson’s. It’s basically because if I have a choice between doing something interesting and tidying the house, I will do the interesting thing (laughing).

A- I understand (laughing).

115 – Having Parkinson’s can be quite time consuming. I mean just in terms of belonging to groups and writing newsletters and all of those sorts of things. And they all take time and also just looking after yourself takes longer than it used to take. It takes ages to just, you know, to get up and get washed. You just sort of do things slower.

A – It just takes longer to get yourself together.

115 – It does, there's no doubt about that. And also you've got all of these pills to take and loads of doctors and hospital appointments and all of that, so. I mean, I was saying to this other guy, that I am also a member of our GP's patient participation group. GP practices are setting up, well the government is encouraging them to set up these groups that have some of the GP's, some patients and the receptionists and they talk to each other and do stuff.

A – That's really great because from what I have heard some GP's are not as "good"

115 – My GP is brilliant, I mean he doesn't know much about Parkinson's but he tries and he listens, he's a very good listener!

(more discussion about the GP)

115 – So he asked me to be part of this group and I now write their newsletter along with the Kensington and Chelsea newsletter. And it is quite consuming. I mean I am not an English type graduate, I was a mathematician so...I mean I have not, I am not someone who has spent a lot of time writing. I mean...I like writing but it takes me quite a long time. I have to write quite a few times before it comes out the way I want it to. But I quite enjoy doing it really but that is quite time consuming really.

A – And it does it takes time. Because of those things being so time consuming.

115 – I don't find hovering very easy. I mean this isn't just being lazy but it really does my back in but PE is quite good. But it would be nice, we really do have to get a load of stuff out of our house. We have inherited...both of our families are no longer around so we have stuff from both families.

(more discussion about getting things out of the house and other family member's issues)

115- Leaving work kind of coincided with joining the ENB classes and so it was really good at the time because I think I would have...I mean, I was used to having a community of people I saw regularly, so you don't end up seeing them as regularly. You see the ones you are close to but you don't see a lot of them and also, I would have missed the students because you get close to the students as well. And so those two things coincided so it was...I didn't really miss work and I'm sure that was part of it.

(Discussion about husband and his work...)

A – And that's really what this part of the interview is about is whether you are still feeling active and as though you can participate in things.

115 – Oh absolutely!

A – Great, this is a huge part of what we want to look at as well is does that change at all across the time we are together, either good or bad, and I think that is a very important part of it. The last kind of area they touch on in this questionnaire that I am trying to use asks about things like hobbies, so going out for dinner or to the theatre, going to the movies, anything like that.

115 – I don't go to the movies as often as I used to. My daughter is really passionate about the movies and as a family we used to go pretty much every Sunday the three of us. This was even after she left home. And that's kind of petered out now partly because well for me I often drop off in the movies. I mean I just cannot...and that's a medication thing, and it's frustrating when you go and fall asleep. I find it quite hard to stay awake right through a whole film in the evenings, even if I haven't been drinking before hand (laughs). And I mean she has no shortage of people to go to the movies with so we've tended to...

A – Stop doing that.

115 – Well we haven't talked about it really, it has just kind of happened. We have a tradition that if it is someone's birthday we go to the theatre but otherwise, it is expensive. But we still go probably once every couple of months.

A – This is the thing, there are so many reasons why...I mean those were just a few examples with movies or the theatre. Basically there are a variety of reasons why these things...you know, stop happening. I mean for me, for me I know you just get into your own busy lives and it just stops but it's one of those things that we come back to, is it the Parkinson's that's stopping you to do things or is it by chance or other reasons that this is happening? But it sounds like even though the medications may make you sleepy or things like that, that you would still attempt to.

115 – Oh sure and you know if it's something that's maybe less effort than you would be less likely to fall asleep I suppose.

A – Yes well this is really what this section was about is whether the Parkinson's is stopping you from doing the things in society that you would like to do and it doesn't sound like it is.

115 – No I don't think it is.

A – That's great...!

Brief discussion about how it is different for everyone and kind of depends on what your life was like before the Parkinson's but she still goes for dinner with friends.

Participant 116 (Case Study Three)

A – So I've written out some questions because it's sometimes a little easier to have a target. So the first question I have is can you see any connections or links between what we've been doing in class, either what we've been doing this term or for the past year? Any connections between what we've done in class and any changes that you've seen in yourself, physical or mental? And of course, if there are no changes, that's fine too. I'm just looking to see if there is any kind of link between anything that you feel has changed or enhanced and what we've done in class.

116 – Yes I think there are two things, one is physical and the other is social. Physically, as I said before it is hard to distinguish the effect of dance but I think it does help and quite often it is the non-physical things that are helping as much as anything.

A – Absolutely, I completely agree. There are a lot of mental health and wellbeing things that I think we are touching on and one of them is the social part of it. And you said physically it is hard to distinguish between what is actually being enhanced.

116 – Well I have no doubt it has helped on the good side not the bad side.

A – Absolutely this is the thing that so many people are clueing in to is that it is a physical activity and so it must be better than not doing anything at all and sitting right?

116 – Yes.

A – And clearly it is and it is part of my job for this project really to try and figure out what are the various components of the class and what are...as we go with the physical measurements and we see very specific things that might be changing across time. For me I am looking particularly at posture and balance and stability and coordination when we walk and how we swing our arms with our legs and if that is enhancing as we work. But you're right it is very difficult to distinguish exactly what, if anything, has actually changed, unless you have the measurements to say it has. So I completely understand. And the social as well, you feel that that's really important?

116 – There's a very good example. Last Sunday, we went to a birthday party with some old University friends that knew that I had Parkinson's but when I mentioned I was doing ballet they were totally intrigued.

A – Yes I am sure they were. A lot of people are when we say that we're doing ballet!

116 – Yes that's part of the point that because I am doing ballet I have a handy topic of conversation.

A – You certainly do!

116 – People are really intrigued by it.

A – That's really good!

116 – So that again is kind of a social boost, boost to mental health.

A – Yes it gives you something to talk about and share with other people. That's great! And do feel the social part of being here is something that is also, is helping you or not so much?

116 – Oh yes it helps a lot.

A – Ok so the group and being part of the group?

116 – Yup!

A- It is, we were saying it is a lovely group to be a part of and I really do feel like there is some sort of magic that Danielle has created with this group. It's, I feel, it is different from other groups, other Parkinson's support groups maybe or things like that. Do you visit any Parkinson's support groups?

116 – I don't, no.

A – I really truly feel that it is something that...we all get together but it is not something that is two hours of focusing on Parkinson's. It's two hours focusing on the art of dance, and it just so happens that everyone there has Parkinson's, you know, it's not focused (on Parkinson's.)

116 – I agree that that's the right approach!

A – It is, I believe so as well, I really do. I think a lot of people have brought forward that idea that it is nice to not have...Parkinson's support groups are great but a lot of the focus is on the medications and the nurses, hospitals that kind of thing as they should be because that's what they are there for. But it is nice to have something quite different, something there like enjoying a new art form or activity outside of that. So there is physical, social, so that is good. Where I kind of wanted to go with that is, do you take part in any other physical activities like dancing possibly, on a regular basis like you would with dance?

116 – Yes I do, there is this Tai Chi thing!

A – Oh yes, do you do Tai Chi?

116 – To be precise what happens is it lasts about an hour and they start with some warming up exercises and I go to that but I'm afraid I wimp out on the actual...

A – It's fine, I have never done Tai Chi before but I can imagine it is quite a hard class to get through.

116 – Yes, what I find is that the second part when they are changing to more Tai Chi is very elegant, quite balletic but slow and boring and what I want is the physical exercise.

A – Absolutely and the kind of actions that you would do at the beginning of the Tai Chi class, are those like a warm up? Like walking around the space kind of things?

116 – We stand a bit, it's kind of like physical training, there are a whole series of exercises for example (demonstrates an action), and sort of bending using the back.

A – That's great!

116 – And part of it...so we count up to 10 for every exercise but for some we count in Cantonese. Because the originator is from Hong Kong!

A – Ok so that makes sense. Absolutely, that is really a great thing. Are there a lot of people that do that as well or is it a big class like you would have here or is it quite small?

116 – It is enormous! This fall there was about 40.

A – Wow, oh my gosh! That's a lot of people in one class doing Tai Chi but I can imagine the beginning part, and that's what you want, that's the physical exertion. I've seen...is it very slow, going through different poses but constantly moving?

116 – The proper Tai Chi, yes that's right.

A – Ok, I've seen it but never been part of a class before. That's good. So first of all is there anything else other than Tai Chi? That's really interesting that you're doing that. Is there anything else?

116 – Not really, I do a small amount of walking and occasionally bicycling.

A – Great yes you were talking about the cycling the other day. So, similar question really that I asked about the dancing, do you feel that the Tai Chi is giving you anything specific, umm, strength in certain areas of the body that's been beneficial for you perhaps?

116 – I think it helps maintain the muscles but I think the main thing is simply bending. I have no back problems and I think that is partly because every morning I do these bending exercises.

A – Absolutely, yes. And how often are these Tai chi classes as well?

116 - Every morning!

A – That's so amazing. This is thing, we were saying that you know the dancing, it's great but it's once a week and then we have breaks because we have to. But then when we start back in September and we've had a long break... But with Tai Chi, it's lovely to have that every morning. And is it quite close to where you live. So you can just kind of walk there?

116- I think it is about less than half a mile and it's through the park anyway.

A – What a lovey way to start the morning as well. That's wonderful P. And it's a ritual would you say, you do it every morning?

116 – Yes! Occasionally I might not go but on average it's probably 6.5 days a week.

A – That's wonderful. So there's probably a lot going on there that's really helping you I would say and as you say, it's muscle maintenance. So it's maintaining a certain level of tonus or strength I'm sure, but it also might be preventing you from certain injuries perhaps. Like your back is feeling great!

116 – I think preventative is the right word.

A – That's excellent.

116 – You didn't ask about the political aspect?

A – No, no I haven't even gone towards the political aspect. I'm more focused on the physical but please, anything you would like to say.

116 – Well there's this little bandstand in the park and that's where we meet. Because when it's raining we are all huddled in inside.

A – I was going to say, not nice with the weather we're getting this summer!

116 – But there's a bit that happened there last night, the council agreed to spend £3000 doing up the bandstand!

A – Oh my gosh, really, oh wow! So then you're going to have a better place to do this essentially.

116 – Yup!

A – Oh that's so nice and because when it's nice weather assumingly you would be out on the lawn on the grass. Is that something... is there a difference do you feel being in the bandstand vs. being outside on the grass?

116 – No we tend to congregate around the bandstand with the Chinese statue and some people are inside and some out. I think that makes no difference.

Further discussion about this

A – And then walking and cycling, you were mentioning cycling the other day and it is very interesting that it is easier you find than walking. And that running can be easier than walking. And I have been thinking about this a lot as you told me this. I have been trying to brainstorm about why that might be and the things I was telling you as well. I think there is a certain rhythm we get into. Certainly with walking it might be a bit more difficult to get into that rhythm but running and cycling may be easier. I was thinking maybe that's something that is key to that movement being so much easier than a walk for instance. Do you feel, and I am not so sure how much you would cycle?

116 – Quite rarely at the moment.

A – I wasn't quite sure, would you say weekly or?

116 – Probably monthly!

A – Ok and do you feel like you are getting anything from walking lots or doing those cycling sessions that...Do you feel different after those sessions?

116 – Certainly walking is a bit difficult anyway so I tend to not do that much walking. Cycling I do have one problem which is sense of balance, so I tend to wander around as well.

A – Well that's a difficult one as well.

116 – Same as running really there is the question of balance.

(more discussion about what we are measuring in the current project with regards to dynamic vs. static stability)

A – So that's great, that kind of gives me an idea. I just wanted to get an idea of what other things people are doing and if they feel that there is a difference. And maybe I can just pose the question to you, do you feel that dance is giving you anything else that we haven't said so far, that other forms of activity wouldn't?

116 – It is cultural as well!

A – A cultural experience.

116 – But I've always been keen on that to other people's surprise.

A – Ya I know it is great that you are able to talk about it and then have other people say or think "oh, really?!" (laugh). "where did that come from?". Have you been interested in ballet in previous years?

116 - Yes, but not to the same extent because of the sheer price of it.

A – Well that's great. It is a cultural experience and as I say it's experiencing an art form and a physical activity as well and not just being there to talk about the condition but to be with others who have the condition to talk about and support

something else and try something else and to fall in love with another physical activity. It's lovely experience. That's great, well I think I am going to leave that section because I think I have a good idea of that kind of thing. Is there anything else, before we move on, that you think dance is giving you that you feel other activities would or wouldn't?

116 - I do think something about the memory. I think sometimes the ballet exercises are very complicated. It can be a little frustrating actually.

A – They are complex and I think sometimes...I mean, I know especially this last term, there are lots of things that I had difficulty with. The stamping and clapping and singing, that one, I looked over to Sara and she was like (worried face) and I was like I know! It was very complex, the rhythms were complex and it was very hard to get that but I understand what you mean about the choreography of some of these exercises being intricate and they are long.

116 – Yes.

A – So it requires you to remember something and more often than not most of us just follow Danielle rather than having memorized it we just follow and have a leader. But I do think that it can help with memory and it's an interesting thought. But as you say it can be frustrating as well when you can't remember what comes next.

Ok, so maybe let's go on to the second section that I wanted to look at and then if there's anything else that pops into your head about dance in relation to other forms of activity please do let me know. Because this is a major question that I think I am really going to have to try and brush away all of the stuff, and say, ok...what is dance providing that maybe Tai chi wouldn't or running maybe wouldn't? Those kind of things you know.

The other area that I wanted to touch on is this idea of independence in society and the amount of assistance that you feel you need and if you feel your Parkinson's is holding you back from anything that you would like to do. So these are, all of these questions are from a validated questionnaire but I thought it would be nice to chat rather than you having to check the boxes. And I think you get more information this way. So the first area that they touched on in this questionnaire was looking at assistance with chores that require you to leave the house. So these would be things like groceries, going to get food, picking up prescriptions or picking up things from the shops. Do you feel that you want to do this or can do this independently or do you feel you need assistance with these kinds of things?

116 – No I would do that independently.

A – Ok and is there, do you find you have any trouble doing these things, stability if that's an issue, or are you pretty comfortable going out there and doing these activities on your own.

116 – I am entirely comfortable.

A – Good

116 – What happens is that I go to Tai Chi with a little run in the middle. I do Tai Chi and then go to the store, might pick up some bread, and then home.

A – Oh that's handy, so you can kind of grab those things as you go.

116 - Yes!

A – Perfect!

(Discussion about tai chi unrelated to benefits and other little things about the interviews across the week and bus strikes)

A – Ok great. So that's good that you feel independent and entirely comfortable with those situations. So also, the next area that they touched on is things at home so active homemaking. These could be things like cleaning, food preparation, gardening, any kind of house repairs, anything like that, any everyday stuff that you have to deal with in the home. Do you still feel that you are able to do that quite comfortably?

116 – Yes!

A – Great! And I know a few people have talked about needing to be careful in kitchens and that kind of thing. Do you feel that you are quite open in the kitchen, you feel like you're fine in the kitchen?

116 – Yes!

A – Great! And then the last area in this section and it's kind of the bigger question is, well the questionnaire has about 10 questions about this and I am kind of wrapping it into one main question looking at how you spend your time. This is basically asking if you still feel you can do the things that you still want to do, hobbies for instance like going out and playing cards, going to the movies, going for a nice dinner, these kinds of things. Do you feel you are still able to do those activities and also do you feel you are still able to do those things with the people you want to do them with or do you feel your Parkinson's is holding you back from doing these things in some way?

116 – I still go out a fair amount and one thing that's always been with me is I have always been willing to get involved in societies and things like that. So I am a member of about 3 or 4 different societies. It naturally causes meetings and those sorts of things.

A – You're right, when you get yourself involved in these things, your schedule can be quite packed I imagine.

116 – Well because I have a background in computer and IT I tend to do the computer side of it.

A – And remind me again are you retired now?

116- Depends what you mean by retired!

A – I know it's kind of a tough one because there was a question in this questionnaire about how you spend your time in terms of occupation and work and I had kind of assumed most people had retired from their occupation or their career. But I could be very wrong and I am making an assumption and probably shouldn't. So I was just wondering if that is something you are still doing or if these things are now your jobs?

116 – Well they are but in addition...I was made redundant from my computer job at the age of 60 and decided to be a freelance translator and it was ideal for a semi-retired situation.

A – Oh that's wonderful. So you still have something on the go there a little bit.

116 – Yup!

A – Oh that's wonderful. Good for you! That's a good way of keeping up to date and aware of things.

116 – Mentally alert as well. So it's quite a good test of memory. I still remember a lot of words and when I start forgetting words that I should know than that's a bad sign.

A - Well, yes it could be a sign of a lot of things but, I was talking to a few people this morning about how the symptoms of Parkinson's and the symptoms of ageing are sometimes similar and difficult to distinguish. For instance, balance and falls. So it's not necessarily just a Parkinson's symptom. There are a lot of elderly people that fall often and don't have Parkinson's so it's interesting, the same with memory.

These kinds of things remembering things and words, there are trends that are similar to these other conditions as well so it can be really quite difficult from a research standpoint as well. But you're right, it's a good test and a good way to keep your mind active. I am glad it is helping you to keep in it. And it's something that you obviously enjoy as well so that's important to keep in there. So that is wonderful, you can still do a lot of the things that you want to do then through these things and keeping active that way. That's nice, it's one of the things that we are trying to look at, of course independence and how much do we need assistance with things but also are you still able to do the things that you want to do. If you wanted to go somewhere, is that not going to be a problem or is that going to be a problem?

116 – I think what could be a problem is I haven't done a lot of travelling in recent years and I think travelling could be problematic.

A – Yup travelling is always a difficult one. There is a lot involved there. But I guess on the whole in terms of hobbies or anything you do on a regular basis like

going to these events and you are able to do them quite fine and you enjoy them which is great.

116 - Yes!

A – And do you visit, do you have family in the area or are they all dispersed?

116 – We have them local.

A – Oh good so you have people around you can see.

116 – For example, one or two days a week our daughter and her daughter will come over and my wife will babysit.

A – Oh that's great and how old is the little one?

116 – 15 months

(Discussion about something unrelated to interview)

Participant 119 (Case Study Four)

A – Ok so with the interviews that I've been doing so far, I wanted to focus on two things. Basically, the first was, one of the main questions that I'm getting a lot recently about the research is, "what is it about dancing that's benefiting people?" A lot of people think ok, dance for people with Parkinson's, obviously dancing is going to be helpful, it's a physical activity so it's better than doing nothing. So this kind of got me thinking, I really do have to deal with this question of what is it about the dancing that is maybe different than Tai chi, or Pilates, or another exercise class. What is it about the dancing that's actually helping them and can we say or encourage dance over something else, right?

And so this is what we are trying to kind of investigate and research into. So I'm going to ask you a few questions in relation to those things in the first and the second bit is just to look at your participation in society and how you feel in terms of independence. And if you feel you have a certain level of independence or if there is a lot of assistance that you need with various different things. And this is actually a part of a longer questionnaire looking at participation in society. And I kind of thought, you guys have already had to do so many questionnaires for me and so I thought it would be nicer to have a chat in an interview. So those are the two areas that I wanted to look at today so we will just briefly run those things. So the first kind of question that I kind of have on my paper, first of all, the dance sessions that we are doing at ENB, do you see connections or links with what you are doing in class and what we've been doing for the past year, past term with any changes you've noticed in your self, in your body, your mind, anything? Do you feel the dancing is affecting you?

119 – Yes, it makes me happy when I'm there. Happy, mentally good. And that's to do, apart from the dancing which is very interesting, it's the personalities of all those who are there.

A – It is, it's a very magical space. I really do feel the personalities...do you feel the teachers, the group members, everybody?

119 - Well's it's certainly the teachers....Dr. Sara and yourself. And the welcome that we even got at your Roehampton University. Everybody, so nice! And could you be any nicer than Danielle and Becky [English National Ballet Dance for Parkinson's teachers], and all the staff there.

A – Yes and they do such a good job.

119 – Exactly!

A – They do such a good job, their organization, they are in tune with what people need in those exercises and what they're trying to get out of those exercises, they know.

119 – And you see you go to some places and you are in a situation and you say ‘Yes Madame’ and then you think “oh I have to listen to her.” There’s none of that, they’re so good.

A – I’m so glad to hear that.

119- And that means that a lot. Go to some place where you are genuinely wanted and the fact that you are disabled, it doesn’t mean a darn thing.

A – Not at all, what matters is you being there and not the disability.

119 – That’s right.

A – That’s good. I am glad that you feel that and that’s coming across as clearly as it is. That’s great. So this is really good and I can see the mentality side of things...you are feeling happy and that you feel wanted, this is exactly what the purpose is and that’s what it’s there for. Do you feel any physical things, these are more mental things?

119 - That’s right.

A – Any physical changes, as a result, ummm coordination, ummm strength, balance, are any of things improving or do you feel that they are staying the same?

119 – Well I suppose slight improvement.

A – Slight.

119 - Slight, not...you see I had lost my confidence when I got Parkinson’s

A – Yes, a lot of people do.

119 – Afraid to cross over the street you know and even afraid driving. Won’t go on the motorway, I stay around the spaces that I know. But so, I know that it helps me. As I say, I am much better in some ways, you know.

A – Absolutely certain things are better than maybe others.

119 – That’s right, but and, how can I put it. I am not a shaker or a mover in any way, but rhythm, when it starts you want to go don’t you. And you feel much better.

A – You do, I don’t know what it is. We were saying, some people say they sleep better at night and they feel just generally happier.

119 - Ya that’s another thing ya. I sleep better. Because I wasn’t sleeping with Parkinson’s. Because I was a great sleeper, but then to get Parkinson’s and not sleep. So I think owe that to English National Ballet and your research.

A – Ya, I'm really excited about (I talk about what the research is aiming to do and how drug therapy may not address all symptoms)

119 – I think those drugs are dreadful. You're a zombie!

A – Now are you on?

119 - I'm on patches.

A – I think I knew that because of the forms.

119 – But the tablets make me sick.

A – Well yes that's for a lot of people with tablets. From what I have heard there are some horrible side effects.

(a little break as she left something in studio)

A – So that's good. Ok, so we have a good understanding of how dance is helping. Some of the things that you feel are that you happier, more confident with certain things, you're sleeping better, ummm, anything else, any other physical things that are being enhanced? We said slightly better perhaps with things like balance and stability.

119 – I think my balance is slight slightly better. Can't say.

A – It makes sense because honestly what I think as well...we are dancing once a week. In order to see such big improvements in balance it is suggested that you dance multiple times per week. So it makes sense that you would say slight because it may be but probably quite small because of the frequency.

119 – That's right.

A – Are you taking part in any other physical activities at the moment?

119 – Well no just here (Kensington and Chelsea support group).

A – And was J saying that there is Pilates and is there Tango?

119 - Yes, we do have Tango and I love the Tango because it is very strict. But the tango, it seems to me preferable. I prefer the tango.

A – That's good to know, and do you think...the music is so...

119 – I think so, I think it's the music and it's the music in the ballet too.

A – Absolutely. The music is strong. There are strong beats and strong rhythms. And he is very strict Anthony. I have been to one of his classes before and he allows you to both lead and follow. And I love that because I think there are benefits from both.

119 – That's right and oh yes it's the same kind of movement most likely in the ballet.

A – Yes very strong at times.

119 – Ya that's exactly like the ballet. The ballet excites me, going to the ballet excites me.

A – As in going to a show?

119 – Yes but going there on a Saturday excites me.

A – That's really good that it excites you, for a variety of reasons I am sure. But it's nice that you feel motivated to go and I think that's a huge part of it. I was saying a lot of people are given home exercises to do but...

119 – Don't do them!

A – Exactly, the motivation to actually do them....it's so hard!

119 – You have to be with people to...

A – You need that motivation and you need somebody to help push you. I feel that with my own exercising and you just need that little bit of a push otherwise you may not push yourself. That's good. And the tango gives you this as well. And so other than these things, these are the only activities that you are doing?

119 - That' right, ya!

A – Ok good. I am going to leave it there. Before we close off that section is there any thing else? I think there are a lot of similarities between the benefits that you would be getting from things like Tango and things like Ballet. But are there any differences or really the benefits that you would be seeing from both are...

119 – Of course, the benefits I get from the ballet are greater. I do enjoy the Tango. The hour and a half or two hours that I spend it's a big

A – Yes well it is more regular you could say and you are doing more of it than the tango so that makes a huge difference.

119 – And you know meeting nice human beings is...

A – Huge, yup. Makes a huge difference.

119 - It does, rather than meeting some nasty person.

A – It would demotivate you to do the class itself. When the people are nice you can enjoy the experience more.

119 – You're alive!

A – Exactly. good. And with the ballet, doing it more and having the nice people I think the main reasons why ballet is giving you the greater benefits then...

119 – Yes, sure.

A – Anything else in that collection or are those the main reasons why you feel you are getting more benefit from the ballet do you think?

119 – Well it's the dance, music, personalities, and just the atmosphere.

A – The whole package, really great to hear. Well I am going to leave it at that for this section but that's really good that I have that information. So the next kind of part that we were looking at is independence in everyday activities. The first thing, there are kind of three main sections so I kind of put it in to 3 different questions and the first one being in chores that require you to go outside of the house. So these would be things like going to groceries, going to pick up prescriptions, to the chemist, that kind of thing just those everyday chores that we end up doing. Do you feel that you can do those things independently or do you feel that you need assistance with those kind of things?

119 – No I can do it!

A – And do you find that you have any issues in doing those things independently or do you feel quite comfortable.

119 – Oh I am... I do my shopping and I do ummm, my chemist and I'll go to the local post office. I do all of that on my own. And umm, the only thing is that I have a lady who comes in once a week and she cleans my flat for me.

A – Ok that's good. I lot of people do that actually and I have just written that down because the next question relates to activities in the house. So active homemaking, things like cleaning, maybe gardening, umm house maintenance.

119 – Well I live in a flat so there's no gardening and she does the cleaning and I just keep it clean.

A – So you maintain the cleaning. That's great and I think it's helpful to have that.

119 – Exactly, but I have a garden down there to and I go down and sit

A – And read, that's great. And food preparation, cooking.

119 - I do all of that myself.

A – Great!

119 – And when there are guests for dinner I do that all too.

A – Perfect, because that leads on to that last section. First we focus on chores that ask you to go outside of the house, second was chores in the house and the last part is about how you spend your time and if there are hobbies or things that you like to do. This could be playing cards with people, going to the movies, going out for dinner, having guests over, these kind of things. Do you feel that you are still able to take part in these activities or do you feel that your Parkinson's is somehow stopping you?

119 – No, not yet and I wouldn't allow that. Mentally I wouldn't allow that because I have quite a few dinners, people over, you know, and coming soon a few people that I worked with were all getting together and they are coming over to me. And that will be about 8 or 10 you know.

A – That's really nice to have that group of people.

119 – That's right. But I keep on having people for dinners or lunch whatever. Mostly it's lunch on a Sunday or something.

A – That's nice to do.

119 – But I know I need to be very...

A – Out there

119 – Determined.

A – Determined, Yes that's a good way of saying it. Do you feel that Parkinson's is stopping you from doing the things you want to do to participate in society?

119 – No!

A – That's good to hear that! Great...well those are all of the questions that I wanted to ask today.

Participant 114 (Data used for Chapter Seven results but not for a case study)

A – One of the main questions I get with this research is why dance? What is it about dance that we would want to advocate for or encourage dance in comparison to other forms of physical activity. A lot of people have said to me, “well of course dance is beneficial, it’s a physical activity, this group needs physical activity, it’s like any other exercise.” This is what I get from other people and I say “yes, but I believe there is something else going on there as well.” I think dance has some additional things that maybe we can’t get from other activities. And I don’t know that, that’s the investigation, that’s what I am trying to determine...is there something else about dance?

114 – Well I think there is.

A – That’s great, well that’s really what I want to talk about really.

114 – Well I think, if you’re asking me now are you?

A – I am, yes go for it.

114 – Well I think being together and simple things like as part of dance, I mean it is a way of communicating isn’t it. Holding hands for example, moving, looking at someone.

A – Yes, eye contact, touch.

114 – Ya, I mean all of that is very important I think. I mean you can say that in that sort of group because everyone, you know, they’re all nice people.

A – Yes, open to it.

114 – You know what I mean, we are a friendly group and I think that frees things up a bit. People feel more willing to become involved and for those that can’t speak as well probably, communicate that way.

A – Exactly, through their body.

114 – I mean the movement, the touching, the dancing, and whatever is another way really.

A - It’s exactly what I’m thinking as well. It’s another way to express and while some can do it through voice and facial expression some of these things go away as the Parkinson’s progresses.

114 – They do!

A – And to be able to try and express or experience things through the body...

114 – Well you know we don't laugh as much as we should and sometimes we look very very serious and we don't realise how we're looking.

A – Yes laughing is important

114 – I mean some people look at me quite shocked sometimes because if I'm not thinking, I can look pretty grimm, you know what I mean?

A – I can too, I sometimes just go into my (resting face)!

114 – Ya but it's particularly so with Parkinson's people, we don't realise always and it can be very off-putting to other people. Within a Parkinson's group we know about it, we know what to expect, so it doesn't really put us off.

A – No, that's true. It's nice to...to not have to explain it or have to justify why.

114 – That's right, ya!

A – You're all together.

114 – And that's why that group worked well yesterday!

A – Yup, groups that know each other.

114 – Exactly the same situation and I mean there was some hand holding and so on. But here particularly there is music as well. Now music motivates people, most people doesn't it?

A – It certainly does. It motivates people to move.

114 – So I don't think we can go wrong if you put...if you've got a programme and you put some dance and music into it, there are not many people who wouldn't get involved and it's the bit I enjoy the most, here really,

A – Is when you're working as a group?

114 – Ya I think so but there are certain things that don't appeal to me too much but that's bound to be the case isn't it?

A - It's bound to be the case in any class, any dancer in any class you can imagine that there will be some things where people say "that's really exciting and interesting" and other people may say, "That really doesn't interest me". I get that all the time with my students when I'm doing a lecture and some things really hit the button and some things are like "I could really be somewhere else right now!"

114 – Yes, and it depends how you are on the day and we're all different everyday really so I mean I want to introduce more music to the Chelsea group!

A – That's great, as you say music is a huge motivator!

114 - Ya that's why I was talking about the Zumba yesterday.

A – Yes I think that's a great idea. We would have to find someone who is a certified teacher but I think it's a great idea to do it.

114 – Well, I like something with a bit more go really.

A – A bit more activity.

114 – Almost like the music here!

A – Ya absolutely. I was talking to someone yesterday about how a lot of the work we do may not increase heart rate until we get to the end. When we are doing our marches at the end it certainly can help with that.

114 – It does ya! I mean we do Tango at Chelsea periodically. Now I think we need to take that a stage further to get more music into it and more movement, you know what I mean. All we're doing really is learning the steps.

A – Ya you need more of an experience.

114 – Well I think so. It's very very important for Parkinson's to have that, the community I think.

A – It really is, I feel like there's a lot of benefits that we are trying to look at with this stuff. But you are right, I think there's the danger in some dance classes with what you say is going on in Tango with just learning the steps, learning or trying to perfect the technique.

114 – Yes I mean we're not looking for experts really!

A – No, you're right it can get too far that way and it needs to be more about moving to the music.

114 – Yes I think so. I mean some of them are very good in the group here aren't they?

A – They are actually.

114 - In terms of their very artistic, the movements are good. Now I'm not really that way inclined, you know what I mean. I'm not that creative in that way. I may be creative in other ways. So I find it...like when, when Danielle says be creative in your movements, it's not really my thing, you know what I mean.

A – Yes I know, and it is sometimes very hard for people to do that because it is on the spot, it's improvisation essentially where you are trying to make up something on the spot.

114 – It's not a bad thing, it's not a bad thing. In fact it's probably helping to release some of the tension in way. But there is one person in that group and

I won't tell you who it is who told me it scares him to death. When Danielle says that, it frightens him to death.

A – Yes it is hard. It's not a surprise because I think a lot of people, even though that one individual said that, I bet you there are not a lot of people in the room who would say I feel completely confident and comfortable doing that. I think a lot of people do hesitate with that and of course all the more reason for Danielle to push that because we are trying to get through that barrier of feeling hesitant about doing our own movements.

114 – Yes there's nothing wrong in doing it.

A – But I agree, in a dancer setting, who was talking about contact improvisation yesterday...it is something that for dancers even in a university it's a very scary thing because it's creating your own movement. But it's also working with the weight of someone else's body and you trusting someone else to catch you. So it's a nerve wrecking thing and not surprising that there is a bit of hesitation there. So it's fine.

114 – I'm sure there is a lot of thought into what's being done in the class because you can tell that really! Because...I mean it flows well!

A – It does and there is a lot for me with regards to the measurements that I am looking at. Anything where we have to twist and opening up and doing these wings in the arms...really important as I am looking at stiffness.

114 – Well that's one of my problems.

A – There you go. Stiffness is a main symptom of Parkinson's.

114 – My neck, the arms and particularly the ankles. In my case, particularly the ankles. But that's been worked on by exercise, by massage.

A – And this is just it, I feel like the movements that they are incorporating are actually helping with this. If we are going to be stiff and rigid, trying to open up and twist, that will only help the rigidity and stiffness.

114 – Yes, Carmella (Pilates teacher) is trying more things now. You were interviewing....

Small discussion about previous Kensington and Chelsea Group class and others in that support group

A – Yes well that answers that question well and I kind of have a good idea of what's coming out of the dancing for you and I understand the music is a very important tool for you.

114 – Well it is for me and I'd like to do more.

A – Ya I feel like we need more sessions per week. It's just too hard.

114 - Except...you know, this has come to end for a couple of months and it's such a shame really.

A - It is because it's quite a large break before September rolls around again. And as we were saying yesterday it would be so nice if there was a way of putting together something that you guys could practice at home. There has to be a way that you can practice at home on your own but then it is really difficult to motivate yourself to do it when you are not in the group.

114 – You are dead right!

A – Ya it's hard and I know a lot of people have been given exercises by their physiotherapists or GP's.

114 – Well, yes I am going to do some exercises this afternoon. I'm doing an action programme with NHS. It doesn't cost anything. Now it's not because of the Parkinson's, though they do provide that in some areas but not in all areas. But it's because of a cardiac issue, so I've been doing something with them for almost a year but we just a few weeks to go. I moved from their general programme to something a bit more specific for an hour in the local gym and we do weights and we do treadmill and rowing and all those sorts of things. And that really gets your heart going and makes you sweat as well so we have a quarter of an hour wind up, half an hour of real action, and she's a great instructor, she really gets us going. And then we have a quarter of an hour wind-down and it's very well done. Now I was referred for that by a GP. And this was because of concern over blood pressure.

A – That's great, and though you started doing it because of the cardiac issues and blood pressure do you still feel that it is helping your Parkinson's?

114 – Yes!

A – And how so?

114 – It's a big help, now this could go on for another....so we will see.

A – Oh that's really wonderful!

114 – And I take the blood pressure once a month and they have the results and the GP and so on.

A – Do you feel like, and I am sure there must be with things like weights and treadmill and rowing and all these things that you are doing there. Do you feel there are certain benefits that you are getting there?

114 – Oh yes, I mean my consultant...I was diagnosed over 4 years ago. I had a tremor in the right hand for quite awhile and so I was in denial for quite awhile. When I eventually went and they pursued it and I went to the consultant, they did all of the tests, the usual ones, including a brain scan and eventually said well, you definitely have Parkinson's. But don't worry there is medication and so on.

So really I'm on 3 different drugs because my consultant says rather than concentrate on 1 and give you a lot of 1, I'd rather spread it out amongst 3 drugs

A – And do you feel that's working quite well?

114 – Ya now I see him every 6 months and the message I am getting from him is that it might be progressing a little bit but...

A – Not that much?

114 – Yes which is good to hear. Now I think all of these things I'm doing are helping. I mean you've got to try and lead a normal life.

A – Yes and you all are doing a great job with that, with continuing with all of these activities.

114 – Yes I mean I do Shigan on a Monday morning.

A – Oh that's cool, so what is involved with that?

114 – Yes, do you know about that?

A – I don't know as much.

114 – It's like Tai Chi.

A – Ok and it...

114 – It relaxes you too but it also involves movements.

A – And going into poses.

114 – Yes and that's a great help as well. And that's for an hour on Monday morning. And then of course I am with the Chelsea group as well, but that's only twice a month.

A – Yes it is hard when it is not as frequent. It has to be regular.

114 – I need another session somewhere so I'm looking for that.

A – I think this is wonderful. You have a Monday morning session, your action programme and then the dancing as well and although we are breaking it's still great.

114 – Oh I think that's, you know, it all helps.

A – It does and as you say it may be helping to slow the progression of your condition perhaps.

114 – Oh ya I am sure it is but you know, I mean, I am involved. I think you can, with Parkinson's, it's disabling isn't it. And it creates a lot of tiredness. You know if I have two or three busy days, I can have a day where I am pretty knackered. But that applies to everyone.

A – Yes we are all that way if we have a long day.

114 – So I am not unique, we are all, most of us, are trying this and doing other things as well and I don't think you want to be focusing on Parkinson's things all of the time.

A – No of course not!

114 – So I am also involved in the Leukaemia association and I am doing certain things in the church as well. But I know some of the others are as well so I am not unique.

A - Yes they are and that's the great part about these interviews is that I am learning so much about what you do and what you enjoy. And I have heard about a range of activities.

114 – Now I am keen on railways and steam trains and steam engines and all that kind of thing, so I get involved with that to a certain extent. My background is farming so anything related to that, countryside.

A – Oh that's lovely and this kind of leads on to my next section really so that's great. So the next section is actually about your independence and how independent you feel in society. And there is a questionnaire that I am basing these questions on and I thought that I have asked you guys to tick enough boxes so I wanted to just ask you in the interview. So I have taken the questionnaire and kind of summarized them in 3 different questions.

And the first one is about your independence in activities that require you to go outside of the house, so this can be things like going to get groceries or going to get a book from the library, these kind of everyday things that we all have to do. Do you feel that you can do these things independently at this moment?

114 – Yes, usually, I mean I feel quiet confident now. There was a time about 6 months ago when I didn't feel quite as independent but I am a pretty independent person.

A – Ok and do you know why that was that you didn't feel as independent?

114 – I don't know why but I mean I don't know, it's not like that so much. Like when I came to get on a bus. I used to think am I actually going to make or will I fall or will I fall off. I mean, there is no sort of logical reason for saying that because I can move, you know what I mean?

A – Yes you are very mobile and active. Just had some second guessing thoughts.

114 – So I don't think it is a major thing but it's worth mentioning. But no I do all of those things, I do go to the library and take books out and I go to the chemist. None of it's a problem. More a problem can be at home.

A – This is my next question so you are right on board with my thoughts. My next question was to do with activities at home.

114 – Well when you know I have a shower everyday or sometimes twice if I am exercising but I like to have a bath as well often late at night and once I slipped trying to get out and I really did something to my back. That's one of the things that I like to have someone about just in case. I have a logger so that...I've never actually asked him to help but I have warned him that I might actually. And there was a time a couple of months ago that I fell over in the bedroom and I thought well it's been ages since I fell over, why did I fall? I think maybe I turned too quickly or in the wrong way or something and that's the thing with Parkinson's. You sometimes...I couldn't understand why I fell over. So I think you have to be aware and maybe, particularly at home. It's difficult to explain.

A – Yes I do think that maybe the house presents more obstacles. It is a confined space. And of course in the kitchen there are things that are hot and a lot of caution that we need to take.

114 – I can cope with the kitchen at the moment. It's more, it's not hazardous, it's more when your walking down the street on the footpath and your balance isn't quite right and you're wandering a bit. I'm a bit sort of embarrassed about that. And I think if there is someone behind me, they must think I am drunk or something. And it happens particularly when you're tired, so you have to be cautious.

A – Yes and people may not know, so they would maybe make assumptions.

114 – No you don't know and they may not even notice. But you notice, because people with Parkinson's tend to walk slower than they believe they are walking. Take smaller strides than we should do. So I mean I notice it because I think I am walking normally and then people start overtaking me.

(more discussion about how busy London is outside of interview questions)

Appendix 12: Analysis Map

Table 7.4 Participant Time Points of Analysis

Participant Number							
Dancing Group	SEPT. 2012	DEC. 2012	APR. 2013	JUL. 2013	DEC. 2013	APR. 2014	JUL. 2014
101	✓	✓	✓	×	×	✓	×
102	✓	✓	✓	×	×	✓	✓
103	✓	✓	×	✓	×	✓	✓
104	✓	✓	×	✓	✓	✓	×
105	✓	×	✓	×	✓	×	✓
106	✓	✓	✓	✓	×	×	✓
107	✓	✓	✓	✓	×	×	×
108	✓	×	✓	✓	✓	✓	✓
109	✓	×	×	✓	✓	✓	✓
110	×	✓	×	✓	✓	×	×
111	✓	✓	✓	✓	✓	✓	✓
112	✓	✓	✓	✓	✓	✓	✓
113	×	×	✓	✓	×	✓	×
114	✓	✓	✓	✓	✓	✓	✓
115	✓	✓	✓	✓	✓	✓	✓
116	✓	✓	✓	✓	×	×	✓
117	×	×	✓	✓	✓	×	×
118	✓	×	✓	✓	✓	✓	✓
119	✓	✓	✓	✓	✓	✓	✓
120	✓	✓	✓	✓	✓	×	✓
121	✓	✓	✓	✓	✓	✓	✓
122	×	✓	✓	✓	✓	✓	✓
123	×	✓	✓	✓	✓	✓	✓
124	✓	✓	✓	✓	×	×	✓
125	×	×	×	✓	✓	✓	✓
Control Group							
201	×	×	✓	✓	✓	✓	✓
202	×	×	✓	✓	✓	✓	✓
203	×	✓	✓	✓	✓	×	✓
204	✓	✓	✓	✓	✓	×	×
205	✓	✓	✓	×	✓	✓	✓
206	✓	✓	✓	×	✓	×	✓
207	✓	×	×	✓	×	✓	✓
208	✓	✓	✓	✓	✓	✓	✓
209	✓	✓	✓	✓	×	✓	✓
210	×	✓	✓	✓	✓	×	✓
211	×	×	✓	✓	✓	×	✓
212	✓	✓	✓	✓	✓	✓	✓
213	✓	✓	✓	✓	✓	✓	✓
214	✓	✓	✓	✓	×	×	✓
215	×	×	×	×	✓	✓	✓

* The checks represent when that participant attended the testing session and the “X” denotes when participants missed that particular session. Each participant has at least two testing sessions highlighted and most have three sessions highlighted. The first two sessions represent the short-term analysis and the first and third highlighted session in the row represent the long-term analysis

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